

PRIVACY OF MEDICAL RECORDS

HEARINGS BEFORE A SUBCOMMITTEE OF THE COMMITTEE ON GOVERNMENT OPERATIONS HOUSE OF REPRESENTATIVES NINETY-SIXTH CONGRESS

FIRST SESSION

ON

H.R. 2979 and H.R. 3444

TO PROTECT THE PRIVACY OF MEDICAL RECORDS MAINTAINED BY MEDICAL CARE FACILITIES, TO AMEND SECTION 552a OF TITLE 5, UNITED STATES CODE, AND FOR OTHER PURPOSES

APRIL 4, 9, 11; JUNE 14; JULY 9, 14; AND SEPTEMBER 17, 1979

Printed for the use of the Committee on Government Operations



PRIVACY OF MEDICAL RECORDS

HEARINGS BEFORE A SUBCOMMITTEE OF THE COMMITTEE ON GOVERNMENT OPERATIONS HOUSE OF REPRESENTATIVES NINETY-SIXTH CONGRESS

FIRST SESSION

ON

H.R. 2979 and H.R. 3444

TO PROTECT THE PRIVACY OF MEDICAL RECORDS MAINTAINED BY MEDICAL CARE FACILITIES, TO AMEND SECTION 552a OF TITLE 5, UNITED STATES CODE, AND FOR OTHER PURPOSES

APRIL 4, 9, 11; JUNE 14; JULY 9, 14; AND SEPTEMBER 17, 1979

Printed for the use of the Committee on Government Operations



74.07-511-8

U.S. GOVERNMENT PRINTING OFFICE

COMMITTEE ON GOVERNMENT OPERATIONS

JACK BROOKS, Texas, *Chairman*

L. H. FOUNTAIN, North Carolina
DANTE B. FASCELL, Florida
WILLIAM S. MOORHEAD, Pennsylvania
BENJAMIN S. ROSENTHAL, New York
FERNAND J. ST GERMAIN, Rhode Island
DON FUQUA, Florida
JOHN CONYERS, Jr., Michigan
CARDISS COLLINS, Illinois
JOHN L. BURTON, California
RICHARDSON PREYER, North Carolina
ROBERT F. DRINAN, Massachusetts
GLENN ENGLISH, Oklahoma
ELLIOTT H. LEVITAS, Georgia
DAVID W. EVANS, Indiana
TOBY MOFFETT, Connecticut
ANDREW MAGUIRE, New Jersey
LES ASPIN, Wisconsin
HENRY A. WAXMAN, California
FLOYD J. FITHIAN, Indiana
PETER H. KOSTMAYER, Pennsylvania
TED WEISS, New York
MIKE SYNAR, Oklahoma
ROBERT T. MATSUI, California
EUGENE V. ATKINSON, Pennsylvania

FRANK HORTON, New York
JOHN N. ERLNBORN, Illinois
JOHN W. WYDLER, New York
CLARENCE J. BROWN, Ohio
PAUL M. McCLOSKEY, Jr., California
THOMAS N. KINDNESS, Ohio
ROBERT S. WALKER, Pennsylvania
ARLAN STANGELAND, Minnesota
M. CALDWELL BUTLER, Virginia
LYLE WILLIAMS, Ohio
JIM JEFFRIES, Kansas
OLYMPIA J. SNOWE, Maine
WAYNE GRISHAM, California
JOEL DECKARD, Indiana

WILLIAM M. JONES, *General Counsel*
JOHN E. MOORE, *Staff Administrator*
ELMER W. HENDERSON, *Senior Counsel*
JOHN M. DUNCAN, *Minority Staff Director*

GOVERNMENT INFORMATION AND INDIVIDUAL RIGHTS SUBCOMMITTEE

RICHARDSON PREYER, North Carolina, *Chairman*

ROBERT F. DRINAN, Massachusetts
GLENN ENGLISH, Oklahoma
DAVID W. EVANS, Indiana
PETER H. KOSTMAYER, Pennsylvania
TED WEISS, New York

THOMAS N. KINDNESS, Ohio
M. CALDWELL BUTLER, Virginia
JOHN N. ERLNBORN, Illinois

EX OFFICIO

JACK BROOKS, Texas

FRANK HORTON, New York

TIMOTHY H. INGRAM, *Staff Director*
ROBERT GELLMAN, *Associate Counsel*
EUPHON METZGER, *Secretary*
THOMAS G. MORR, *Minority Professional Staff*

CONTENTS

Hearings held on—	Page
April 4.....	1
April 9.....	305
April 11.....	499
June 14.....	597
July 9.....	755
July 14.....	809
September 17.....	877
Texts of H.R. 2979, H.R. 3444, and H.R. 5935.....	3, 38, 91
Statement of—	
Anderson, Bette B., Under Secretary, Department of the Treasury; accompanied by H. Stuart Knight, Director, Secret Service	727
Beigler, Dr. Jerome S., chairperson, Committee on Confidentiality, American Psychiatric Association	357
Brown, Barry S., prosecutor of Monroe County, Ind., representing the National District Attorneys Association	943
Coons, Gale, executive director, Indiana Dental Association, Indianapolis, Ind.	857
Crawford, Marshall, R., senior director, Blue Cross and Blue Shield Associations	553
Dawes, Dennis W., administrator, Hendricks County Hospital, Danville, Ind.; accompanied by John Render, general counsel to Indiana Hospital Association.....	844
English, Michael J., Office of Legal Adviser, St. Elizabeths Hospital	623
Erickson, Dr. James H., Director, Bureau of Medical Services, Public Health Service	607
Freedman, Alfred M., M.D., president and chairman, National Commission on Confidentiality of Health Records; accompanied by Robert Belair, counsel; and Toby Levin, assistant executive director	232
Geller, Henry, Assistant Secretary, Communications and Information, U.S. Department of Commerce; accompanied by Arthur Bushkin, Director, information policy program, National Telecommunications and Information Administration	141
Gordis, Dr. Leon, representing the Society for Epidemiologic Research, and the Association of American Medical Colleges	461
Hofmann, Dr. Adele, American Academy of Pediatrics	963
Holbert, Kathleen, surgery coordinator, Johnson County Hospital, Franklin, Ind.	834
Huseland, Stanley A., director, governmental affairs, Blue Cross and Blue Shield of Indiana, Indianapolis, Ind.; accompanied by Donald J. Van Dyke, vice president, marketing administration division	823
Johnson, Emery A., M.D., Director of the Indian Health Service, Health Services Administration.....	597
Keeney, John C., Deputy Assistant Attorney General, Criminal Division, Department of Justice; accompanied by Abbe Lowell, Special Assistant to the Deputy Attorney General; Francis M. Mullen, Jr., Inspector-Deputy Assistant Director, Criminal Investigation Division, Federal Bureau of Investigation; and Pat Watson, Intelligence Division, FBI	756
Krever, Justice Horace, Commissioner, Royal Commission of Inquiry Into the Confidentiality of Health Records, Toronto, Ontario; accompanied by Harvey Strosberg, Counsel	500
Libassi, Peter, General Counsel, Department of Health, Education, and Welfare; accompanied by Darrel Grinstead, Acting Associate General Counsel	183

IV

	Page
Lowe, Richard, Deputy Inspector General, Department of Health, Education, and Welfare.....	801
Marsden, Dr. John, executive director, Lilly Research Laboratories, Eli Lilly & Co., Indianapolis, Ind	813
Moore, Dr. Donald, director, Larue Carter Psychiatric Hospital, Indianapolis, Ind	864
Norman, C. Robert, administrator, Heritage House Convalescent Center, Shelbyville, Ind., on behalf of the Indiana Health Care Association; accompanied by Janet Coers, administrator, Heritage House Children's Center, Shelbyville, Ind.....	853
Poppewell, Dr. Arvine G., president, Indiana State Medical Association, Indianapolis, Ind.....	859
Prince, Harwood, director of medical records, Indiana University hospitals, Indianapolis, Ind.....	861
Reindl, J. Michael, assistant executive director, Indiana Pharmaceutical Association, Indianapolis, Ind	819
Rogers, Jane, director of legislative affairs, American Medical Record Association; accompanied by Lorraine Volz, director, medical record department, Thomas Jefferson University Hospital, Philadelphia, Pa	306
Shattuck, John H. F., director of the Washington office of the American Civil Liberties Union	576, 643
Troyer, Leon, Woodbridge, Va	941
Wolfe, Dr. Sidney M., Public Citizen Health Research Group	877
Letters, statements, etc., submitted for the record by—	
Anderson, Bette B., Under Secretary, Department of the Treasury: Submissions to additional subcommittee requests	749-753
Beigler, Dr. Jerome S., chairperson, Committee on Confidentiality, American Psychiatric Association: Material relative to the hearings	365-453
Brown, Barry S., prosecutor of Monroe County, Ind., representing the National District Attorneys Association: Prepared statement	951-962
Crawford, Marshall R., senior director, Blue Cross and Blue Shield Associations:	
Guidelines on preserving confidentiality of medical records	557-559
Prepared statement	563-576
English, Michael J., Office of Legal Adviser, St. Elizabeths Hospital: Prepared statement	626-635
Erickson, Dr. James H., Director, Bureau of Medical Services, Public Health Service: Prepared statement	609-922
Freedman, Alfred M., M.D., president and chairman, National Commission on Confidentiality of Health Records: Supplemental material relative to the hearings	241-304
Geller, Henry, Assistant Secretary, Communications and Information, U.S. Department of Commerce: Prepared statement	142-164
Gordis, Dr. Leon, representing the Society for Epidemiologic Research, and the Association of American Medical Colleges:	
May 30, 1979, letter to Chairman Preyer concerning liability for nonconsensual disclosures of identifiable medical records	471-472
Prepared statement	473-497
Hofmann, Dr. Adele, American Academy of Pediatrics: Prepared statement	966-974
Holbert, Kathleen, surgery coordinator, Johnson County Hospital, Franklin, Ind.:	
Additional comments	842-843
Malpractice Research, Inc., screens patient records.....	835
Huseland, Stanley A., director, governmental affairs, Blue Cross and Blue Shield of Indiana, Indianapolis, Ind.: Request form	829
Johnson, Emery A., M.D., Director of the Indian Health Service, Health Services Administration: Prepared statement	600-606
Keeney, John C., Deputy Assistant Attorney General, Criminal Division, Department of Justice:	
August 1979, letter to Chairman Preyer re Department's comments regarding H.R. 2979	792-800
Prepared statement	757-767
Knight, H. Stuart, Director, Secret Service, Department of the Treasury:	
August 13, 1979, letter to Chairman Preyer re various State laws pertaining to the access of medical/mental health records.....	747

June 28, 1979, letter to Chairman Preyer re guidelines utilized by Secret Service field offices when contacting hospitals and mental institutions	742-743
Prepared statement	732-735
Krever, Justice Horace, Commissioner, Royal Commission of Inquiry Into the Confidentiality of Health Records, Toronto, Ontario:	
Executive orders	502-507
Specimen reports made by private investigators	513-535
Libassi, Peter, General Counsel, Department of Health, Education, and Welfare:	
April 19, 1979, memorandum from Darrel Grinstead, re obtaining medical information under false pretenses	190-192
How present legislation ties in with the provisions of H.R. 3 of 1977 ...	205
Intent of the bill	204
Obtaining of records	199
Prepared statement	209-231
Moore, Dr. Donald, director, Larue Carter Psychiatric Hospital, Indianapolis, Ind.: Prepared statement	867-875
Mullen, Francis M., Jr., Inspector-Deputy Assistant Director, Criminal Investigation Division, Federal Bureau of Investigation: Prepared statement	774-779
Rogers, Jane, director of legislative affairs, American Medical Record Association:	
Additional material relative to the hearings	321-335
Prepared statement	336-356
Shattuck, John H. F., director of the Washington office of the American Civil Liberties Union:	
Prepared statement	577-596
Supplement to statement and additional material	658-726
Strosberg, Harvey, Counsel, Royal Commission of Inquiry Into the Confidentiality of Health Records, Toronto, Ontario: List of the member companies and groups of the Insurance Bureau of Canada	539-540
Wolfe, Dr. Sidney M., Public Citizen Health Research Group:	
Comments before the Occupational Safety and Health Administration, U.S. Department of Labor, March 30, 1979	883-886
Prepared statement	895-940

APPENDICES

Appendix 1.—Letters submitting statements regarding privacy of medical records legislation	979
A. Letter from Maurice Grossman, M.D., professor of psychiatry, Stanford University School of Medicine, submitting statement on privacy of medical records legislation	979
B. Letter from A. Edward Doudera, executive director, American Society of Law & Medicine, submitting report on privacy of medical records legislation	1012
C. Letter from John E. Affeldt, M.D., president, Joint Commission on Accreditation of Hospitals, submitting statement on privacy of medical records legislation	1037
D. Letter from Mylio S. Kraja, director, National Legislative Commission, the American Legion, submitting statement on privacy of medical records legislation	1050
E. Letter from Dale Tooley, district attorney, second judicial district, State of Colorado, submitting testimony on privacy of medical records legislation	1062
F. Letter from Edmund B. Rice, legislative representative, American Hospital Association, submitting statement on privacy of medical records legislation	1086
G. Letter from James H. Sammons, M.D., executive vice president, American Medical Association, submitting statement on privacy of medical records legislation	1128
Appendix 2.—Letters commenting on privacy of medical records legislation	1157
A. Letter from William Foley, Director, Administrative Office of the United States Courts	1157
B. Letter from Robert Ellis Smith, publisher, Privacy Journal	1160
C. Letter from Arthur Goshin, M.D., president, Health Care Plan	1161

	Page
D. Letter from Boyd Thompson, executive vice president, American Association of Professional Standards Review Organization	1163
E. Letter from Christopher C. Fordham III, M.D., dean, University of North Carolina Medical School	1165
F. Letter from Jerome S. Beigler, M.D., clinical professor of psychiatry, University of Chicago	1166
G. Letter from W. G. Anlyan, M.D., Duke University Medical Center	1168
H. Letter from Donald A. Brennan, executive vice president, Group Health Cooperative of Puget Sound	1172
I. Letter from Seymour Jablon, director, National Research Council	1176
J. Letter from Elma L. Griesel, executive director, National Citizen's Coalition for Nursing Home Reform	1178
K. Letter from James L. Oberstar, M.C., House of Representatives	1179
L. Letter from Philip H. Taylor, M.D., chairman, Peer Review Systems, Inc	1181
M. Letters from Irwin N. Perr, M.D., J.D., professor of psychiatry, College of Medicine and Dentistry of New Jersey	1183
N. Letter from John H. Romani, Ph. D., president, American Public Health Association	1192
O. Letter from Edward A. Mortimer, Jr., M.D., Case Western Reserve University	1195
P. Letter from John Reckless, M.D., F.A.C.P., the John Reckless Clinic	1198
Q. Letter from Paul L. Thompson, national commander, Disabled American Veterans	1200
R. Letter from Perry L. Taylor, D.D.S., president, Delta Dental Plans Association	1203
S. Letter from Donald H. Schwab, director, Veterans of Foreign Wars of the United States	1206
T. Letter from John F. Heilman, national legislative director, Disabled American Veterans	1209
U. Letter from Faye Wattleton, president, Planned Parenthood-World Population, Headquarters for Planned Parenthood Federation of America, Inc	1216
V. Letter from R. Otto Meletzke, assistant general counsel, American Council of Life Insurance, and David J. Pattison, assistant Washington counsel, Health Insurance Association of America	1223
W. Letter from William M. Hermelin, administrator, American Health Care Association	1227
X. Letter from Boyd Thompson, executive vice president, American Professional Standards Review Organizations	1233
Y. Letter from Marchia Kraft Goin, M.D., chairperson, Committee on Confidentiality, American Psychiatric Association	1234

PRIVACY OF MEDICAL RECORDS

WEDNESDAY, APRIL 4, 1979

HOUSE OF REPRESENTATIVES,
GOVERNMENT INFORMATION
AND INDIVIDUAL RIGHTS SUBCOMMITTEE
OF THE COMMITTEE ON GOVERNMENT OPERATIONS,
Washington, D.C.

The subcommittee met, pursuant to notice, at 10:10 a.m., in room 2247, Rayburn House Office Building, Hon. Richardson Preyer (chairman of the subcommittee) presiding.

Present: Representatives Richardson Preyer, David W. Evans, Peter H. Kostmayer, Ted Weiss, John N. Erlenborn, and Thomas N. Kindness.

Also present: Timothy H. Ingram, staff director; Robert Gellman, counsel; Euphon Metzger, secretary, and Tom Morr, minority professional staff, Committee on Government Operations.

Mr. WEISS [presiding]. Good morning. The Subcommittee on Government Information and Individual Rights of the Government Operations Committee will come to order.

As Mr. Preyer indicated, he has been called to a Standards and Ethics Subcommittee meeting. He will be back shortly. He asked us to proceed until he returns. What I would like to do is to read the opening statement which he had prepared. It will be entered into the record under his authorship. The statement says:

"Today we begin hearings on legislation to protect the confidentiality of medical records. If he were available, our first witness would be Hippocrates, the Greek physician from the fourth century B.C. The Hippocratic oath, which is still in use today, includes this clause:

"'Whatever, in connection with my professional practice, or not in connection with it, I see or hear, in the life of men, which ought not to be spoken abroad, I will not divulge, as reckoning that all such should be kept secret.'

"Life has become more complicated since the days of ancient Greece. A one-sentence oath on medical confidentiality is no longer sufficient to cope with modern medical practice. One of the bills now before the subcommittee, H.R. 2979, is 35 pages long. The difference between one sentence and 35 pages is a striking reflection of the complexity of our society. It may also be viewed as reflecting the tremendous progress in medicine and in the delivery of medical services.

"As we consider this legislation, it is our responsibility to take into account the legitimate information needs of the modern health care system. Researchers, insurers, auditors, and others all have some need for medical information.

"However, we must also take into account the privacy interests of today's patient. Despite all of the changes in medicine in the last 2,000 years, one constant is the patient's desire for privacy. It is this right to privacy that is most threatened by progress.

"The growth in use and availability of personal information is not a characteristic unique to medicine. As the report of the Privacy Protection Study Commission reflects, threats to personal privacy come from many different sources. The need for action was underscored on Monday when Vice President Mondale announced the long-awaited administration initiative on privacy.

"While we are chiefly concerned in these hearings with privacy of medical records, we will begin with a presentation of the administration's general approach to privacy issues. Our first witness is Henry Geller, Assistant Secretary of Commerce for Communications and Information."

That is the chairman's statement.

[The bills relative to the hearings follow:]

TABLE OF CONTENTS—Continued

TITLE I—PRIVACY OF MEDICAL RECORDS

PART A—DEFINITIONS; EFFECT ON STATE LAWS; RIGHTS OF MINORS AND INCOMPETENTS

- Sec. 101. Definitions.
- Sec. 102. Effect on State laws.
- Sec. 103. Rights of minors and incompetents.

PART B—RIGHTS OF ACCESS, CORRECTION, AND NOTICE, AND AUTHORIZED DISCLOSURE

- Sec. 111. Inspection of medical records.
- Sec. 112. Correction of medical records.
- Sec. 113. Notice of record keeping practices.
- Sec. 114. Disclosure of medical records.
- Sec. 115. Authorization for disclosure of medical records.

PART C—DISCLOSURE OF MEDICAL RECORDS WITHOUT SPECIFIC AUTHORIZATION

- Sec. 121. Employee use.
- Sec. 122. Consultation.
- Sec. 123. Admission and health status information.
- Sec. 124. Research.
- Sec. 125. Audits and evaluations.
- Sec. 126. Health and safety.
- Sec. 127. Statutorily mandated disclosures.
- Sec. 128. Secret service or foreign intelligence.
- Sec. 129. Law enforcement functions.
- Sec. 130. Judicial and administrative proceedings.
- Sec. 131. Subpoenas, summons, and search warrants.
- Sec. 132. Other provisions relating to disclosures without specific authorization.

PART D—GOVERNMENT ACCESS, CHALLENGE RIGHTS, AND REPORTING

- Sec. 141. Access procedures.
- Sec. 142. Challenge procedures.
- Sec. 143. Reporting requirements.

PART E—ENFORCEMENT

- Sec. 151. Compliance as a condition for participation in medicare and medicaid programs.
- Sec. 152. Criminal penalty for obtaining a medical record through false pretenses.
- Sec. 153. Civil suits.

TITLE II—AMENDMENT TO TITLE 5, UNITED STATES CODE

- Sec. 201. Amendment to title 5, United States Code.

TABLE OF CONTENTS—Continued

TITLE III—EFFECTIVE DATE AND REGULATIONS

Sec. 301. Effective date.

Sec. 302. Promulgation of regulations.

1 FINDINGS AND PURPOSES

2 SEC. 2. (a) Congress finds that—

3 (1) the right to privacy is a personal and funda-
4 mental right protected by the Constitution of the
5 United States;

6 (2) the collection, maintenance, use, and dissemi-
7 nation of medical information can threaten an individ-
8 ual's right to privacy;

9 (3) the Federal Government is playing an increas-
10 ingly important role in the provision, payment, and
11 regulation of medical services;

12 (4) medical information about an individual is rou-
13 tinely made available to public and private organiza-
14 tions for uses not directly related to the provision of
15 medical services to the individual;

16 (5) in order to prevent unfairness resulting from
17 the misuse of medical information, an individual must
18 be able to exercise more direct control over medical
19 information; and

20 (6) an individual's right to privacy must be bal-
21 anced against the legitimate needs of public and pri-
22 vate organizations for individually identifiable medical

1 information in performing their law enforcement, public
2 health, research, fiscal, and other important functions.

3 (b) The purposes of this Act are—

4 (1) to establish procedures allowing individuals to
5 inspect medical records relating to them and to make
6 corrections in these records; and

7 (2) to define the circumstances under which indi-
8 vidually identifiable medical information may be dis-
9 closed and to whom it may be disclosed.

10 TITLE I—PRIVACY OF MEDICAL RECORDS

11 PART A— DEFINITIONS, EFFECT OF STATE LAW, AND 12 RIGHTS OF MINORS AND INCOMPETENTS

13 DEFINITIONS

14 SEC. 101. For purposes of this Act:

15 (1) The term “accounting” means, with respect to
16 a disclosure, the recording, as part of the medical
17 record from which the disclosure was made, of the
18 date, nature, and purpose of the disclosure, of the
19 name and business address of the person to whom the
20 disclosure was made, and of any written certification
21 provided in order to obtain the record.

22 (2) The term “audit” means [to be supplied].

23 (3) The term “employee” means, with respect to
24 a facility or person, an individual who is employed by,

5

1 responsible to, or performing a function on behalf of,
2 the facility or person.

3 (4) The term “evaluation” means an assessment
4 of effectiveness, efficiency, or compliance with applica-
5 ble legal, fiscal, medical, scientific, or other appropriate
6 standards or aspects of performance.

7 (5) The term “government authority” means any
8 agency or department of the United States, or of any
9 territory or possession thereof, of any State or political
10 subdivision thereof, of the District of Columbia, or of
11 the Commonwealth of Puerto Rico, or any officer, em-
12 ployee, or agent thereof.

13 (6) The term “health research project” means a
14 biomedical, epidemiologic, or health services research
15 project or a health statistics project.

16 (7) The term “health services” means [to be sup-
17 plied].

18 (8)(A) The term “institutional review board”
19 means an Institutional Review Board established in ac-
20 cordance with regulations of the Secretary under sec-
21 tion 474 of the Public Health Service Act.

22 (B) The term “appropriate institutional review
23 board” means, with respect to a health research proj-
24 ect intending to use the medical records maintained by
25 a facility or researcher, (i) the institutional review

6

1 board for the organization sponsoring the project, (ii)
2 the institutional review board (if any) for the facility or
3 researcher, or (iii) the institutional review board for an-
4 other medical facility or institution the medical records
5 of which also are intended to be used in the project.

6 (9) The term "medical care facility" means—

7 (A) a hospital, skilled nursing facility, or in-
8 termediate care facility, or

9 (B) another entity for which approval by the
10 Secretary is required for participation in or cover-
11 age under the program under title XVIII of the
12 Social Security Act or for which certification by a
13 State agency is required for participation in a pro-
14 gram under title XIX of such Act, but only with
15 respect to such provisions of this title as the Sec-
16 retary makes applicable to such an entity by regu-
17 lation,

18 which is approved by the Secretary for participation in
19 or coverage under the program under title XVIII of
20 the Social Security Act or certified by a State agency
21 or participation in a program under title XIX of such
22 Act. Such term also includes an entity of the United
23 States which is a hospital, skilled nursing facility, or
24 intermediate care facility.

1 (10) The term “medical record” means any mate-
2 rial that—

3 (A)(i) contains information relating to the
4 health, examination, care, or treatment of an indi-
5 vidual, or (ii) is to be added to such materials
6 under the provisions of this title, and

7 (B) is in a form enabling the individual to be
8 identified.

9 (11) The term “Secretary” means the Secretary
10 of Health, Education, and Welfare.

11 EFFECT ON STATE LAWS

12 SEC. 102. (a) Except as provided in subsection (b), this
13 title supercedes any State or local laws governing the confi-
14 dentiality of medical records maintained by medical care
15 facilities to the extent that the records of such facilities are
16 subject to this title.

17 (b) This title does not supercede—

18 (1) any restriction on the disclosure of medical
19 records under (A) section 333 of the Comprehensive
20 Alcohol Abuse and Alcoholism Prevention, Treatment
21 and Rehabilitation Act of 1970 or (B) section 408 of
22 the the Drug Abuse Office and Treatment Act of
23 1972,

24 (2) any other such restriction of Federal, State, or
25 local law with respect to disclosure of medical records

1 relating to alcohol or drug abuse, or treatment for such
2 abuse, or

3 (3) any restriction of Federal, State, or local law
4 on access to or disclosure of medical records relating to
5 psychiatric, psychological, or mental health treatment.

6 **RIGHTS OF MINORS AND INCOMPETENTS**

7 **SEC. 103.** The rights of (and obligations with respect to)
8 an individual under this title shall be exercised and dis-
9 charged through—

10 (1) the parent or guardian of the individual, if the
11 individual is under the age of majority (as determined
12 under the laws of the jurisdiction in which the facility
13 is located); or

14 (2) an authorized legal representative of the indi-
15 vidual, if the individual has been declared to be incom-
16 petent by a court of competent jurisdiction.

17 **PART B—RIGHTS OF ACCESS, CORRECTION, AND**

18 **NOTICE, AND AUTHORIZED DISCLOSURE**

19 **INSPECTION OF MEDICAL RECORDS**

20 **SEC. 111.** (a)(1) Except as provided under subsection
21 (b), a medical care facility shall permit an individual to in-
22 spect any medical record that the facility maintains about the
23 individual, and shall permit the individual to have a copy of
24 the record. The individual may, in accordance with section
25 115, authorize another person to inspect or to have a copy of

1 the record and to accompany the individual during the in-
2 spection.

3 (2) A facility may require a written application for the
4 inspection and copying of a medical record under this section
5 and shall respond to a request for such an inspection or copy
6 within 30 days of the date it receives the request.

7 (3) A medical care facility may not charge a fee for
8 permitting inspection of a record under this section. The fa-
9 cility may charge a reasonable fee (no greater than the copy-
10 ing fee imposed on third-party payers) for making a copy of
11 such a medical record.

12 (b) A medical care facility may deny an individual the
13 right to inspect a medical record (or portion thereof) if it de-
14 termines that the inspection might reasonably be expected to
15 cause sufficient harm to the individual so as to outweigh the
16 desirability of permitting access. If the right to inspect is
17 denied, the facility shall permit an appropriate person (as de-
18 fined by the Secretary) designated by the individual to in-
19 spect the record involved.

20 (c) The Secretary shall publish recommended criteria by
21 which medical care facilities can determine, pursuant to sub-
22 section (b), whether the inspection by an individual of the
23 individual's medical records might reasonably be expected to
24 cause sufficient harm to the individual so as to outweigh the
25 desirability of permitting the inspection.

1 CORRECTION OF MEDICAL RECORDS

2 SEC. 112. Not later than 30 days after the date an indi-
3 vidual requests in writing that a medical facility correct a
4 medical record that the facility maintains about the
5 individual, the facility shall either—

6 (1)(A) make the correction requested; (B) inform
7 the individual of the correction that has been made;
8 and (C) upon the request of the individual, inform any
9 person not employed by the facility and to whom the
10 incorrect portion of the record was previously disclosed
11 of the correction that has been made; or

12 (2) inform the individual of (A) the reasons for its
13 refusal to make the correction, (B) any procedures for
14 further review of the refusal, and (C) the individual's
15 right to file with the facility a concise statement set-
16 ting forth the individual's reasons for disagreeing with
17 the refusal of the facility.

18 After an individual has filed a statement of disagreement, the
19 facility, in any subsequent disclosure of the disputed portion
20 of the record, shall include a copy of the individual's state-
21 ment and may include a concise statement of the facility's
22 reasons for not making the requested correction.

1 NOTICE OF RECORD KEEPING PRACTICES

2 SEC. 113. (a) A medical care facility shall, in accord-
3 ance with subsection (b), provide an individual with a written
4 notice of record keeping practices describing—

5 (1) the categories of disclosures from a medical
6 record that the facility may make under part C without
7 the written authorization of the individual;

8 (2) the individual's rights under this title, includ-
9 ing the right to inspect medical records and the right
10 to seek corrections of medical records; and

11 (3) the procedures established by the facility for
12 the exercise of these rights.

13 (b) A notice of record keeping practices (described in
14 subsection (a)) shall be provided to an individual—

15 (1) when the facility first provides services to the
16 individual after the effective date of this title;

17 (2) when the facility first provides services to the
18 individual more than one year after providing a previ-
19 ous notice; and

20 (3) when the facility first provides services to the
21 individual after a substantial change has been made in
22 the notice.

23 (c) The Secretary shall promulgate by regulation a
24 model notice of record keeping practices describing the cate-
25 gories of disclosures and rights of individuals required to be

1 included in notices of record keeping practices under para-
2 graphs (1) and (2) of subsection (a). If a facility's notice of
3 record keeping practices incorporates the model notice pro-
4 mulgated by the Secretary under this subsection, the facili-
5 ty's notice shall be deemed in compliance with the require-
6 ments of paragraphs (1) and (2) of subsection (a) for such a
7 notice.

8 **DISCLOSURE OF MEDICAL RECORDS**

9 **SEC. 114. A medical care facility—**

10 (1) may not disclose a medical record about an in-
11 dividual other than to the individual (under section
12 111) unless either (A) the individual has authorized the
13 disclosure under section 115, or (B) the disclosure is
14 permitted under part C without such an authorization;

15 (2) may not disclose a medical record to any
16 person unless the person is properly identified; and

17 (3) shall, where practicable, limit disclosure of a
18 medical record to information needed to accomplish the
19 purpose for which the disclosure is made.

20 **AUTHORIZATION FOR DISCLOSURE OF MEDICAL RECORDS**

21 **SEC. 115. (a)** For purposes of this title, an individual
22 has authorized disclosure to a person of information in a
23 medical record maintained by a medical care facility only if—

24 (1) the authorization is (A) in writing, (B) dated,
25 and (C) signed by the individual;

1 (2) the facility is specifically named or generically
2 described in the authorization as authorized to disclose
3 such information;

4 (3) the person to whom the information is to be
5 disclosed and the purpose for which the person may
6 use the information are specifically named or generical-
7 ly described in the authorization as a person to whom,
8 and a purpose for which, such information may be dis-
9 closed; and

10 (4) the disclosure occurs before the date or event
11 (if any), specified in the authorization, upon which the
12 authorization expires.

13 (b) An individual may in writing revoke or amend an
14 authorization, in whole or in part, at any time.

15 (c) A medical care facility that discloses information
16 from a medical record pursuant to this section shall maintain
17 a copy of the authorization as part of the medical record.

18 PART C—DISCLOSURE OF MEDICAL RECORDS WITHOUT
19 SPECIFIC AUTHORIZATION

20 EMPLOYEE USE

21 SEC. 121. A medical care facility may disclose a medi-
22 cal record it maintains about an individual, without the au-
23 thorization described in section 115(a), if the disclosure is to
24 an employee of the facility who has a need for the medical
25 record in the performance of his duties.

1

CONSULTATION

2 SEC. 122. A medical care facility may disclose a medi-
3 cal record it maintains about an individual, without the au-
4 thorization described in section 115(a), if the disclosure is to
5 a medical care professional who is consulted by the facility in
6 connection with health services provided to the individual.

7

ADMISSION AND HEALTH STATUS INFORMATION

8 SEC. 123. A medical care facility may disclose a medi-
9 cal record it maintains about an individual, without the au-
10 thorization described in section 115(a), if the disclosure only
11 reveals the presence of the individual at the facility or the
12 provision of services to the individual at the facility, his loca-
13 tion in the facility, and his general condition, and—

14 (1) the individual has not objected to the discolo-
15 sure, and

16 (2) the information does not reveal specific infor-
17 mation about the individual's condition or treatment.

18

HEALTH RESEARCH

19 SEC. 124. (a) A medical care facility may disclose a
20 medical record it maintains about an individual, without the
21 authorization described in section 115(a), if—

22 (1) the disclosure is for use in a health research
23 project (as defined in section 101(6)) which has been
24 determined by an appropriate institutional review board
25 (as defined in section 101(8)(B)) to be of sufficient im-

1 portance so as to outweigh the intrusion into the priva-
2 cy of the individual that would result from the disclo-
3 sure, and

4 (2) the facility has provided to the person to
5 whom the information is disclosed a copy of the notice
6 (published by the Secretary under subsection (c)) of the
7 requirements of subsection (b).

8 (b) Any person who obtains a medical record pursuant
9 to subsection (a) shall—

10 (1) maintain the medical record in compliance
11 with the security standards prescribed by the Secretary
12 pursuant to section 132(b)(1);

13 (2) remove, where practicable, information en-
14 abling individuals to be identified;

15 (3) not disclose in any public report information
16 contained in the record and enabling individuals to be
17 identified; and

18 (4) not further use or disclose the information con-
19 tained in the record and enabling the individuals to be
20 identified, except—

21 (A) for disclosure to an employee of the
22 person who has a need for the information in per-
23 forming his duties under the project,

1 (B) in compelling circumstances affecting the
2 health or safety of any person or involving immi-
3 nent danger of serious property damage,

4 (C) for use in another health research proj-
5 ect, under the same restrictions on use and disclo-
6 sure (including approval by an appropriate institu-
7 tional review board) applicable under this subsec-
8 tion to the original project, and

9 (D) for disclosure to a properly identified
10 person for the purpose of an audit or evaluation
11 related to the project.

12 (c) The Secretary shall publish a notice, available for
13 use by medical care facilities, which accurately describes the
14 conditions, described in subsection (b), for the maintenance,
15 use, and further disclosure of information disclosed under this
16 section.

17 AUDITS AND EVALUATIONS

18 SEC. 125. (a) A medical care facility may disclose a
19 medical record it maintains about an individual, without the
20 authorization described in section 115(a), if—

21 (1) the disclosure is for the purpose of an audit or
22 evaluation, and

23 (2) the facility has provided to the person to
24 whom the information is disclosed a copy of the notice

1 (published by the Secretary under subsection (c)) of the
2 requirements of subsection (b).

3 (b) Any person who obtains a medical record pursuant
4 to subsection (a) shall—

5 (1) maintain the medical record in compliance
6 with the security standards prescribed by the Secretary
7 pursuant to section 132(b)(1);

8 (2) remove, where practicable, information
9 enabling individuals to be identified;

10 (3) not disclose in any public report information
11 contained in the record and enabling individuals to be
12 identified; and

13 (4) not further use or disclose the information con-
14 tained in the record and enabling the individuals to be
15 identified, except—

16 (A) for disclosure to an employee of the
17 person who has a need for the information in per-
18 forming his duties under the audit or evaluation,

19 (B) for disclosure to the person for whom the
20 audit or evaluation is being carried out,

21 (C) in compelling circumstances affecting the
22 health or safety of any person or involving immi-
23 nent danger of serious property damage, and

24 (D) when required by Federal or State law.

1 (c) The Secretary shall publish a notice, available for
2 use by medical care facilities, which accurately describes the
3 conditions, described in subsection (b), for the maintenance,
4 use, and further disclosure of information disclosed under this
5 section.

6 HEALTH AND SAFETY

7 SEC. 126. (a) A medical care facility may disclose a
8 medical record it maintains about an individual, without the
9 authorization described in section 115(a), if the disclosure
10 is—

11 (1) to assist in the identification of a dead person,
12 or

13 (2) pursuant to a showing of compelling circum-
14 stances (A) affecting the health or safety of any person
15 or (B) involving imminent danger of serious property
16 damage,

17 and the facility maintains an accounting (as defined in section
18 101(1)) of the disclosure.

19 (b) Medical records disclosed by a medical care facility
20 to a governmental authority under this section shall not be
21 further disclosed by the authority except, if not otherwise
22 prohibited by law—

23 (1) where necessary to fulfill the purpose for
24 which the record was obtained, or

1 (2) for the purposes, and subject to the conditions
2 (other than any requirement that an accounting be
3 maintained), specified in sections 124 through 131.

4 STATUTORILY MANDATED DISCLOSURES

5 SEC. 127. (a) A medical care facility may disclose a
6 medical record it maintains about an individual, without the
7 authorization described in section 115(a), if the disclosure is
8 to a governmental authority pursuant to a Federal or State
9 law requiring the disclosure of the record to the authority.

10 (b) Medical records disclosed by a medical care facility
11 to a governmental authority under this section shall not be
12 further disclosed by the authority except, if not otherwise
13 prohibited by law—

14 (1) where necessary to fulfill the purpose for
15 which the record was obtained, or

16 (2) for the purposes, and subject to the conditions
17 (other than any requirement that an accounting be
18 maintained), specified in sections 124 through 131.

19 SECRET SERVICE OR FOREIGN INTELLIGENCE

20 SEC. 128. (a) A medical care facility may disclose a
21 medical record it maintains about an individual, without the
22 authorization described in section 115(a), if the disclosure
23 is—

24 (1) to—

1 (A) the United States Secret Service for the
2 purpose of conducting its protective functions
3 under section 3056 of title 18, United States
4 Code (relating to Secret Service powers), under
5 section 202 of title 3, United States Code (relat-
6 ing to the Executive Protective Service), or under
7 Public Law 90-331 (relating to Secret Service
8 protection of Presidential and Vice Presidential
9 candidates), or

10 (B) an authority of the United States author-
11 ized to conduct foreign counter- or positive-intelli-
12 gence activities for the purpose of conducting such
13 activities, and

14 (2) the government authority seeking the disclo-
15 sure provides the facility with a written certification,
16 signed by a supervisory official of a rank designated by
17 the head of the government authority, that the record
18 is being sought for a legitimate Secret Service or for-
19 eign intelligence purpose.

20 (b) No medical care facility, or employee of the facility,
21 shall disclose to any person that a government authority has
22 sought or obtained access to a medical record under this sec-
23 tion.

24 (c) Medical records disclosed by a medical care facility
25 to a governmental authority under this section shall not be

1 further disclosed by the authority except, if not otherwise
2 prohibited by law where necessary to fulfill the purpose for
3 which the record was obtained.

4 LAW ENFORCEMENT FUNCTIONS

5 SEC. 129. (a) A medical care facility may disclose a
6 medical record it maintains about an individual, without the
7 authorization described in section 115(a), if the disclosure is
8 to a government authority, and is—

9 (1)(A) for use in an investigation or prosecution
10 (directed at any person other than the individual) of
11 fraud, abuse, or waste in a program or project funded
12 or operated by a government authority, or (B) to assist
13 in the identification or location of a suspect or fugitive
14 in a legitimate law enforcement inquiry;

15 (2) the government authority seeking the disclo-
16 sure provides the facility with a written certification,
17 signed by a supervisory official of a rank designated by
18 the head of the government authority, that the record
19 is being sought for a legitimate purpose under this sec-
20 tion; and

21 (3) the facility maintains an accounting (as defined
22 in section 101(1)) of the disclosure.

23 (b) Medical records disclosed by a medical care facility
24 to a governmental authority under this section shall not be

1 further disclosed by the authority except, if not otherwise
2 prohibited by law—

3 (1) where necessary to fulfill the purpose for
4 which the record was obtained, or

5 (2) for the purposes, and subject to the conditions
6 (other than any requirement that an accounting be
7 maintained), specified in sections 124 through 131.

8 JUDICIAL AND ADMINISTRATIVE PROCEEDINGS

9 SEC. 130. (a) A medical care facility may disclose a
10 medical record it maintains about an individual, without the
11 authorization described in section 115(a), if the disclosure is
12 not otherwise prohibited by law, is made pursuant to the
13 Federal Rules of Civil or Criminal Procedure or comparable
14 rules of other courts or administrative agencies in connection
15 with litigation or proceedings to which the individual is a
16 party.

17 (b) Medical records disclosed by a medical care facility
18 to a governmental authority under this section shall not be
19 further disclosed by the authority except, if not otherwise
20 prohibited by law—

21 (1) where necessary to fulfill the purpose for
22 which the record was obtained, or

23 (2) for the purposes, and subject to the conditions
24 (other than any requirement that an accounting be
25 maintained), specified in sections 124 through 131.

SUBPOENAS, SUMMONS, AND SEARCH WARRANTS

SEC. 131. (a) A medical care facility may disclose a medical record it maintains about an individual, without the authorization described in section 115(a), if—

(1) the disclosure is pursuant to an administrative, judicial, or grand jury summons or subpoena or pursuant to a search warrant;

(2) the facility is provided a written certification by the person seeking the record that the person has complied with the access provisions of section 141; and

(3) the facility maintains a copy of the summons, subpoena, or search warrant as part of the medical record.

(b) Medical records about an individual disclosed by a medical care facility under this section pursuant to a subpoena issued under the authority of a Federal grand jury—

(1) shall be returned and actually presented to the grand jury;

(2) shall be used only for the purpose of considering whether to issue an indictment or presentment by that grand jury, or of prosecuting a crime for which that indictment or presentment is issued, or for a purpose authorized by rule 6(e) of the Federal Rules of Criminal Procedure;

1 (3) shall be destroyed or returned to the medical
2 care facility if not used for one of the purposes speci-
3 fied in paragraph (2); and

4 (4) shall not be maintained, or a description of the
5 contents of such records shall not be maintained, by
6 any government authority other than in the sealed rec-
7 ords of the grand jury, unless such record has been
8 used in the prosecution of a crime for which the grand
9 jury issued an indictment or presentment or for a pur-
10 pose authorized by rule 6(e) of the Federal Rules of
11 Criminal Procedure.

12 (c) Medical records disclosed by a medical care facility
13 to a governmental authority under this section shall not be
14 further disclosed by the authority except, if not otherwise
15 prohibited by law—

16 (1) where necessary to fulfill the purpose for
17 which the record was obtained, or

18 (2) for the purposes, and subject to the conditions
19 (other than any requirement that an accounting be
20 maintained), specified in sections 124 through 131.

21 OTHER PROVISIONS RELATING TO DISCLOSURES WITHOUT
22 SPECIFIC AUTHORIZATION

23 SEC. 132. (a) Nothing in this part shall be construed as
24 requiring a medical care facility to disclose information not
25 otherwise required to be disclosed by law.

1 (b)(1) The Secretary shall prescribe security standards
2 with respect to the use and maintenance by researchers,
3 auditors, and evaluators of identifiable medical record infor-
4 mation disclosed by facilities under sections 124 and 125.
5 The standards shall establish appropriate administrative,
6 technical, and physical safeguards for insuring the security
7 and confidentiality of these records. The Secretary may pre-
8 scribe different standards for researchers, auditors, and
9 evaluators, and may vary the standards according to the sen-
10 sitivity of the information disclosed.

11 (2) The Secretary shall publish guidelines on how medi-
12 cal care facilities can fulfill the accounting requirement of
13 sections 126 and 129, including suggestions for such methods
14 and procedures as will meet this requirement inexpensively
15 and with minimal disruption to the medical treatment process
16 and to standard record keeping practices.

17 (c) The Secretary shall prepare a notice, for use under
18 section 141(a)(2), detailing the rights of an individual who
19 wishes to challenge, under section 142, the disclosure of the
20 individual's medical record under such section.

21 PART D—GOVERNMENT ACCESS, CHALLENGE RIGHTS,

22 AND REPORTING

23 ACCESS PROCEDURES

24 SEC. 141. (a) A government authority may obtain a
25 medical record about an individual from a medical care facili-

1 ty pursuant to an administrative, judicial, or grand jury sum-
2 mons or subpoena under section 131, if not otherwise prohib-
3 ited by law, only if—

4 (1) there is reasonable cause to believe that the
5 record will produce information relevant to a legitimate
6 law enforcement inquiry being conducted by the gov-
7 ernment authority;

8 (2) except as provided in subsection (c), a copy of
9 the summons or subpoena has been served upon the in-
10 dividual or mailed to his last known address on or
11 before the date on which the summons or subpoena
12 was served on the medical care facility, together with
13 a notice (published by the Secretary under section
14 132(c)) of the individual's right of challenge under
15 section 142; and

16 (3)(A) 14 days have passed from the date of serv-
17 ice or mailing and within such time period the individu-
18 al has not initiated a challenge in accordance with sec-
19 tion 142, or

20 (B) it is ordered by a court under section 142.

21 (b) A government authority may obtain a medical record
22 about an individual from a medical care facility pursuant to a
23 search warrant if, not later than 30 days after the date the
24 search warrant was served on the medical care facility, it
25 serves the individual with, or mails to the last known address

1 of the individual, a copy of the search warrant together with
2 the notice (published by the Secretary under section 132(c))
3 of the individual's right of challenge under section 142.

4 (c)(1) A government authority may apply to an appropri-
5 ate court to delay (for an initial period of not longer than 90
6 days) serving a copy of a summons or subpoena and a notice
7 otherwise required under subsection (a)(2) with respect to a
8 law enforcement inquiry. The government authority may
9 apply to the court for extensions of the delay.

10 (2) An application for a delay, or extension of a delay,
11 under this subsection shall state, with reasonable specificity,
12 the reasons why the delay or extension is being sought.

13 (3) If the court finds that—

14 (A) the inquiry being conducted is within the
15 lawful jurisdiction of the government authority seeking
16 the medical records;

17 (B) there is reasonable cause to believe that the
18 records being sought will produce information relevant
19 to the inquiry;

20 (C) the government authority's need for the
21 record in the inquiry outweighs the individual's privacy
22 interest; and

23 (D) there is reasonable cause to believe that re-
24 ceipt of a notice by the individual will result in—

1 (i) endangering the life or physical safety of
2 any person;
3 (ii) flight from prosecution;
4 (iii) destruction of or tampering with evi-
5 dence;
6 (iv) intimidation of potential witnesses; or
7 (v) jeopardy (with a comparable degree of se-
8 riousness to the circumstances described in
9 clauses (i) through (iv)) to an investigation or offi-
10 cial proceeding or undue delay in trial or ongoing
11 official proceeding,
12 the court shall enter an ex parte order delaying, or extending
13 the delay of, the notice and an order prohibiting the medical
14 care facility from revealing the request for, or the disclosure
15 of, the records.

16 (3) Upon the expiration of a period of delay of notice
17 under this subsection, the government authority shall serve,
18 with the service of the summons or subpoena and the notice,
19 a copy of any applications filed and approved under this sub-
20 section.

21 CHALLENGE PROCEDURES

22 SEC. 142. (a) Within 14 days of the date of service or
23 mailing of a summons or subpoena of a government authority
24 seeking a medical record about an individual from a medical
25 care facility under section 131, the individual may file in the

1 appropriate United States district court or state court a
2 motion to quash the the subpoena or summons, with a copy
3 served upon the government authority (specified in the notice
4 which the individual received under section 131(a)) by deliv-
5 ery or registered or certified mail.

6 (b)(1) Upon receipt of such a motion, the government
7 authority may file with the appropriate court such affidavits
8 and other sworn documents as sustain the validity of the
9 summons or subpoena. The individual may file, within five
10 days of the date of the authority's filing, affidavits and sworn
11 documents in response to the authority's filing.

12 (c) If the court is unable to determine the motion on the
13 basis of the initial filings, the court may conduct additional
14 proceedings as it deems appropriate. All such proceedings
15 shall be completed, and the motion decided, within ten calen-
16 dar days of date of the government authority's filing.

17 (d)(1) A court may only deny an individual's timely
18 motion under subsection (a) if it finds that there is reasonable
19 cause to believe that the law enforcement inquiry is legiti-
20 mate and that the records sought are relevant to that inquiry,
21 and the court shall sustain the motion if it finds that the
22 individual's privacy interest outweighs the government auth-
23 ority's need for the record.

24 (2) The court may assess against a Federal government
25 authority reasonable attorney fees and other litigation costs

1 reasonably incurred in the case of any motion brought under
2 subsection (a) against the authority and in which the individ-
3 ual has substantially prevailed.

4 (e) A court ruling enforcing process under this section
5 shall not be deemed a final order and no interlocutory appeal
6 may be taken therefrom by the individual. An appeal of a
7 ruling enforcing the process under this section may be taken
8 by the individual (1) within such period of time as provided
9 by law as part of any appeal from a final order in any legal
10 proceeding initiated against him arising out of or based upon
11 the medical record, or (2) within 30 days after a notification
12 that no legal proceeding is contemplated against him. The
13 government authority obtaining the medical record shall
14 promptly notify an individual when a determination has been
15 made that no legal proceeding against him is contemplated.
16 After 180 days from the date of the enforcement of the proc-
17 ess, if the government authority obtaining the record has not
18 initiated such a proceeding, a supervisory official of the gov-
19 ernment authority shall certify to the appropriate court that
20 no such determination has been made. The court may require
21 that such certifications be made at reasonable intervals there-
22 after, until either notification to the individual has occurred
23 or a legal proceeding is initiated as described in clause (1).

24 (f) The challenge procedures of this section constitute
25 the sole judicial remedy available to an individual to prevent

1 disclosure of a medical record pursuant to a judicial or admin-
2 istrative summons or subpoena.

3 (g) Nothing in this section shall enlarge or restrict any
4 rights of a medical care facility to challenge requests for a
5 medical record made by a government authority under exist-
6 ing law. Nothing in this section shall entitle an individual to
7 assert the rights of a medical care facility.

8 **REPORTING REQUIREMENTS**

9 **SEC. 143.** In April of each year (beginning with the
10 year after the year in which this Act is enacted), each Feder-
11 al government authority that requests access to medical rec-
12 ords from a medical care facility pursuant to sections 126
13 through 131, shall submit a report to the Speaker of the
14 House of Representatives and the President of the Senate,
15 for referral to the appropriate committees of Congress, which
16 report shall include the number of (1) requests for medical
17 records made under each of such sections, (2) delays of notice
18 sought under section 141(c), (3) successful and unsuccessful
19 challenges made under section 142, in the proceeding calen-
20 dar year, and such other information as the authority deems
21 appropriate.

1 PART E—ENFORCEMENT

2 COMPLIANCE AS A CONDITION FOR PARTICIPATION IN

3 MEDICARE AND MEDICAID PROGRAMS

4 SEC. 151. (a) A medical care facility may not partici-
5 pate and may not continue to participate in the program
6 under title XVIII of the Social Security Act unless the facili-
7 ty provides adequate assurances, and evidence from time to
8 time, to the Secretary of its substantial compliance with the
9 provisions of parts B and C of this title.

10 (b)(1) Except as provided in paragraph (2), a medical
11 care facility may not participate and may not continue to
12 participate in the program of a State under title XIX of the
13 Social Security Act unless the facility provides adequate as-
14 surances, and evidence from time to time, to an appropriate
15 State agency (as determined under regulations of the Secre-
16 tary) of its substantial compliance with the provisions of parts
17 B and C of this title.

18 (2) A medical care facility is not required to provide the
19 assurances and evidence otherwise required under paragraph
20 (1) if it has provided the assurances and evidence required
21 under subsection (a).

22 CRIMINAL PENALTY FOR OBTAINING A MEDICAL RECORD

23 THROUGH FALSE PRETENSES

24 SEC. 152. Any person who, under false or fraudulent
25 pretenses or with a false or fraudulent certification required

1 under this Act, requests or obtains a medical record about an
2 individual from a medical care facility or an authorization
3 from an individual to disclose such a record shall be fined not
4 more than \$10,000, or imprisoned for not more than one
5 year, or both.

6 CIVIL SUITS

7 SEC. 153. (a) Any person aggrieved as a result of—

8 (1) a violation by a medical care facility, govern-
9 ment authority, researcher, auditor, or evaluator of any
10 provision of part B or C of this title, or

11 (2) the commission by a person of an act which
12 constitutes a crime under section 152,

13 may bring a civil action in any appropriate United States
14 district court, without regard to the amount in controversy,
15 or in any other court of competent jurisdiction, against the
16 medical care facility, government authority, researcher, audi-
17 tor, evaluator, or other person, respectively.

18 (b) If the court determines in such an action that a vio-
19 lation or commission has occurred, the aggrieved person
20 may—

21 (1) recover the sum of—

22 (A) actual damages sustained as a result of
23 the violation or commission or \$1,000, whichever
24 is greater, and

1 (B) the costs of the action together with rea-
2 sonable attorney fees as determined by the court;
3 and

4 (2) obtain such other relief, including punitive
5 damages and equitable relief, as the court determines
6 to be appropriate.

7 TITLE II—AMENDMENT TO TITLE 5, UNITED
8 STATES CODE

9 AMENDMENT TO TITLE 5, UNITED STATES CODE

10 SEC. 201. Section 552a of title 5, United States Code,
11 is amended by adding at the end the following new subsec-
12 tion:

13 “(r) Any medical record contained in a system of rec-
14 ords maintained by a medical care facility subject to title I of
15 the Federal Privacy of Medical Records Act shall not be sub-
16 ject to the provisions of subsections (b) through (d), (e)(3),
17 (e)(11), (f)(3), and (g) through (k) of this section, if the mainte-
18 nance and disclosure of the medical record are subject to the
19 provisions of such title.”.

20 TITLE III—EFFECTIVE DATE AND REGULATIONS
21 EFFECTIVE DATE AND PROMULGATION OF REGULATIONS

22 SEC. 301. This Act and the amendments made by this
23 Act shall take effect on the first day of the first calendar
24 quarter beginning more than 180 days after the date of the
25 enactment of this Act.

1 PROMULGATION OF REGULATIONS

2 SEC. 302. The Secretary shall first establish final regu-
3 lations to carry out the amendments made by this Act not
4 later than the first day of the second month that begins
5 before the effective date of such amendments (as specified
6 under section 301).

To protect the privacy of medical information, to amend the Privacy Act of 1974, and for other purposes.

Mr. PREYER (for himself and Mr. GOLDWATER) (by request) introduced the following bill; which was referred jointly to the Committees on Government Operations, Interstate and Foreign Commerce, and Ways and Means

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. This Act may be cited as the “Privacy of
Medical Information Act”.

FINDINGS

SEC. 2. The Congress finds that—

(1) the right to privacy is a personal and fundamental right,

(2) rapidly changing technology permits record-keepers to compile and disseminate more detailed and highly personal information about individuals than ever before,

(3) the collection, maintenance, use, and dissemination of confidential medical information can threaten the individual's right to privacy,

(4) individuals should be able to exercise more direct control over confidential medical information, particularly since the availability of such information to third parties often affects the individual's ability to obtain employment, insurance, medical care, and other important benefits,

(5) all health care providers affect interstate commerce, due to the complex and interrelated nature of the medical care system, and

(6) there is a need for Federal statutory protection of the privacy of medical information maintained by health care providers.

1 TITLE I—REQUIREMENTS APPLICABLE TO

2 MEDICAL CARE FACILITIES

3 INDIVIDUAL'S ACCESS TO MEDICAL INFORMATION

4 SEC. 101. (a) A medical care facility shall (except as
5 provided in subsection (b)), upon request of an individual, pro-
6 vide, at the choice of the individual, (1) the individual, or (2)
7 a person designated by the individual, within twenty working
8 days an opportunity to inspect, and a copy of, any medical
9 information that the facility maintains concerning the
10 individual.

11 (b) A medical care facility shall provide within twenty
12 working days an appropriate person (as defined in regulations
13 of the Secretary) designated by the individual an opportunity
14 to inspect, and a copy of, medical information that the facility
15 maintains concerning the individual, in those circumstances
16 in which the facility determines that the application of the
17 requirements of subsection (a) would be likely to be sufficient-
18 ly harmful to the individual or to another person so as to
19 outweigh the desirability of applying those requirements.

20 (c) A medical care facility may not impose a charge for
21 permitting an inspection of, and may impose only a reason-
22 able charge (in any event no greater than the charge imposed
23 on third persons) for providing a copy of, medical information
24 under this section.

1 CORRECTION OF MEDICAL INFORMATION

2 SEC. 102. (a) If an individual requests that a medical
3 care facility correct medical information that the facility
4 maintains concerning the individual, the facility shall, within
5 ninety calendar days, either—

6 (1) amend or supplement the medical information
7 to make the correction requested, or

8 (2)(A) inform the individual of its refusal to do so,
9 the reasons for the refusal, and of the facility's proce-
10 dures, if any, for further review of the refusal, and

11 (B) permit the individual to file with the facility a
12 concise statement setting forth any correction request-
13 ed, but not made, by the facility, and the reasons for
14 requesting that correction.

15 (b) The facility shall, if the individual so requests, inform
16 the individual of any disclosure that the facility previously
17 made of the information to which a correction has been re-
18 quested, if the facility has maintained a notation of the
19 disclosure.

20 (c) The facility shall provide any person, specifically
21 designated by the individual, to whom the information was
22 previously disclosed a copy of any correction made, and of
23 any statement filed as provided under subsection (a)(2)(B).

24 (d) The facility shall, in any subsequent disclosure of the
25 information to which a correction was requested, include any

1 correction made, and any statement filed as provided under
2 subsection (a)(2)(B).

3 NOTIFICATION OF DISCLOSURE OF MEDICAL INFORMATION

4 SEC. 103. (a) On or prior to the effective date of this
5 Act, a medical care facility shall prepare a notice of the dis-
6 closures that may be made by the medical care facility of
7 medical information concerning an individual without the au-
8 thorization of the individual, and the procedures, if any by
9 which an individual can learn of each such disclosure.

10 (b) A medical care facility shall provide the notice re-
11 quired by subsection (a) to an individual:

12 (1) where reasonably possible, when first provid-
13 ing medical services to the individual, and

14 (2) upon request of an individual who has re-
15 ceived, or may receive, medical care services from the
16 medical care facility.

17 LIMITATION OF DISCLOSURE TO PROPERLY IDENTIFIED
18 PERSONS AND TO PURPOSE FOR WHICH NEEDED

19 SEC. 104. A medical care facility may disclose medical
20 information concerning an individual only to properly identi-
21 fied persons, and (except for disclosures to Federal or State
22 authorities) only to the extent needed to accomplish the pur-
23 pose for which the disclosure is to be made.

1 CONDITIONS FOR DISCLOSURE OF MEDICAL INFORMATION

2 SEC. 105. (a) A medical care facility may not disclose
3 medical information that it maintains concerning an individu-
4 al, except as provided in subsection (b), unless the individual
5 has authorized the disclosure as provided in subsection (d)
6 and the facility has complied with subsection (e).

7 (b) The provisions of subsection (a) shall not apply to a
8 disclosure by a medical care facility—

9 (1) to a person employed by, an agent of, or re-
10 sponsible to, the facility, to the extent that the person
11 needs the information to carry out his duties,

12 (2) to a health care provider, in connection with
13 health services being provided to the individual,

14 (3) consistent with accepted medical practice, to
15 the next of kin or persons with whom the individual
16 has a personal relationship,

17 (4) in compelling circumstances which the facility
18 has in good faith determined will affect the health or
19 safety of the individual or another person, if a notation
20 of the disclosure (and to whom the information was
21 disclosed) is made part of the medical information that
22 the facility maintains concerning the individual,

23 (5) for use in a biomedical, epidemiologic, or
24 health services research project, or a health statistics
25 project, if—

1 (A) the facility reasonably determines that—

2 (i) the disclosure does not violate any
3 limitations placed upon the use or disclosure
4 of the information at the time the information
5 was obtained,

6 (ii) the project cannot reasonably be
7 conducted without the information, and

8 (iii) the importance of the project
9 outweighs the risk to the individual that dis-
10 closure might bring,

11 (B) the person conducting the project pro-
12 vides adequate assurances that—

13 (i) appropriate safeguards will be estab-
14 lished against unauthorized use or disclosure
15 of the information, and

16 (ii) there will be a program to remove
17 or destroy materials enabling the individual
18 to be identified at the earliest time at which
19 removal or destruction can be accomplished
20 consistent with the purposes of the research,
21 unless the recipient presents an adequate jus-
22 tification of a research or health nature for
23 retaining such materials, and

24 (C) the person conducting the project pro-
25 vides adequate assurances that further use or dis-

1 closure of the information will not be made,
2 except—

3 (i) for disclosure to a person employed
4 by, an agent of, or responsible to, the person
5 conducting the project, to the extent needed
6 to carry out the project,

7 (ii) to the extent necessary to meet a
8 medical emergency or to prevent a crime
9 that could result in physical injury to an in-
10 dividual, provided that the information dis-
11 closed will be limited to that necessary to
12 provide medical assistance or to secure the
13 protection of the individual who may by
14 injured,

15 (iii) in compliance with a judicial order,
16 including a search warrant or lawfully issued
17 subpena, where the purpose of the judicial
18 order is to assist inquiry into an alleged vio-
19 lation of law by the person or agency main-
20 taining research records: *Provided, That—*

21 (I) any information so disclosed
22 shall not be used as evidence in any ad-
23 ministrative, legislative, or judicial pro-
24 ceeding against anyone other than the
25 agency or person maintaining the

1 record, their employees, or a person to
2 whom the information was disclosed,

3 (II) any information so disclosed
4 shall not be used as evidence, or other-
5 wise made public, in a manner that an
6 individual to whom information in the
7 research record pertains may be identi-
8 fied, unless identification of the individ-
9 ual is necessary to establish the viola-
10 tion of law, and

11 (III) an individual identified in any
12 information to be made public in identi-
13 fiable form shall be given notice prior to
14 such publication and given an opportu-
15 nity to contest the necessity of such
16 publication,

17 (iv) to qualified and properly identified
18 persons for the purpose of conducting man-
19 agement audits, financial audits, or program
20 evaluation: *Provided, That—*

21 (I) the audit or evaluation is au-
22 thorized by statute if it is conducted by
23 a Government authority, or authorized
24 by statute or by contractual agreement
25 if conducted by any other person, and

1 (II) that no subsequent use or dis-
2 closure of the information will be made
3 by the auditor or evaluator, except in
4 accordance with this paragraph, and
5 (v) for a research or statistics purpose:
6 *Provided, That the person or agency disclos-*
7 *ing the records—*

8 (I) determines that such use or dis-
9 closure does not violate any limitation
10 under which the record or information
11 was provided, collected, or obtained,

12 (II) determines that the research
13 or statistics purpose for which the dis-
14 closure is to be made cannot be reason-
15 ably accomplished unless the informa-
16 tion is provided in individually identifi-
17 able form, and warrants the risk to the
18 individual that additional exposure of
19 the information might bring,

20 (III) requires the recipient to es-
21 tablish reasonable administrative, tech-
22 nical, and physical safeguards to pre-
23 vent unauthorized use or disclosure of
24 research records, and to remove or de-
25 stroy the information that allows the in-

1 dividual to be identified at the earliest
2 time at which removal or destruction
3 can be accomplished consistent with the
4 purpose of the research project, unless
5 the recipient presents an adequate justi-
6 fication of a research or health nature
7 for retaining such materials, and

8 (IV) secures a written statement
9 attesting to the recipient's understand-
10 ing of, and willingness to abide by, the
11 conditions of this Act,

12 (6) to persons presenting appropriate evidence of
13 their official status who state in writing that they need
14 the information—

15 (A) for a Government public health investi-
16 gation, for a Government investigation of activi-
17 ties of the facility, or for a Federal, State, or local
18 government audit or evaluation purposes, or

19 (B) to carry out a program under title V,
20 part B of title XI, title XVIII, or title XIX of the
21 Social Security Act, or other Government pro-
22 gram providing payments to, or concerned with
23 activities of, the facility, or to conduct an investi-
24 gation concerning fraud, abuse, or waste under
25 those programs,

1 if a copy of the written statement is maintained and
2 made available to the individual on request,

3 (7) to persons who state in writing that they need
4 the information for an audit or evaluation purpose, or
5 for the purpose of carrying out a program providing
6 payments to the facility, if—

7 (A) the person to whom the information is to
8 be disclosed provides adequate assurances that ap-
9 propriate safeguards will be established against
10 unauthorized disclosure of the information, and
11 that there will be a program to remove or destroy
12 materials enabling the individual to be identified,

13 (B) the person to whom the information is to
14 be disclosed provides adequate assurances that
15 further use or disclosure of the information will
16 not be made, except—

17 (i) for disclosure to persons carrying out
18 the audit or evaluation purpose, or carrying
19 out the program providing payments,

20 (ii) in compelling circumstances affecting
21 the health or safety of the individual or an-
22 other person, or

23 (iii) pursuant to compulsory legal proc-
24 ess, and

1 (C) a copy of the written statement is main-
2 tained and made available to the individual on
3 request,

4 (8) pursuant to a Federal or State law requiring
5 disclosure to a public health authority,

6 (9) to a law enforcement authority, pursuant to a
7 Federal or State law that requires specific types of in-
8 formation to be reported to that authority,

9 (10) revealing only the presence of the individual
10 at the facility at a particular time or the provision of
11 services at a particular time to the individual, his loca-
12 tion, or his general medical condition, if—

13 (A) the individual has not objected to the dis-
14 closure, or

15 (B) the disclosure is to a Government au-
16 thority pursuant to a legitimate law enforcement
17 inquiry,

18 (11) to a Federal authority pursuant to an admin-
19 istrative summons or subpoena, search warrant, judicial
20 subpoena, or formal written request of the Federal au-
21 thority, if the Federal authority certifies in writing to
22 the facility that the Federal authority has complied
23 with the applicable requirements of sections 203
24 through 206,

1 (12) to a State authority pursuant to an adminis-
2 trative summons or subpoena, search warrant, judicial
3 subpoena, or formal written request of the State author-
4 ity, if, at the time of the request, the State authority
5 certifies in writing to the facility that the State author-
6 ity has complied with the applicable requirements
7 under section 207,

8 (13) to a Government authority, if, at the time of
9 disclosure or as soon thereafter as practical, the au-
10 thority certifies in writing to the facility, in a document
11 signed by a supervisory official of a rank designated by
12 the head of the Government authority, that the infor-
13 mation is immediately needed to prevent the imminent
14 danger of—

15 (A) serious property damage, or

16 (B) flight to avoid prosecution,

17 (14) to a Government authority, if the authority
18 seeks the information under the Federal Rules of Civil
19 or Criminal Procedure or comparable rules of State
20 courts in connection with litigation to which the Gov-
21 ernment authority and the individual are parties,

22 (15) to a Government authority, if the authority
23 seeks the information pursuant to an administrative
24 subpoena issued by an administrative law judge or com-
25 parable State official in an adjudicatory proceeding

1 subject to section 554 of title 5, United States Code,
2 or comparable provisions of State law to which the
3 Government authority and the individual are parties,
4 (16) to—

5 (A) a Federal authority authorized to conduct
6 foreign intelligence or counterintelligence activi-
7 ties, if the Federal authority certifies in writing to
8 the facility, in a document signed by a supervisory
9 official of a rank designated by the head of the
10 Federal authority, that the information is needed
11 to accomplish a purpose of conducting such activi-
12 ties, or

13 (B) to the Secret Service, if the Secret Serv-
14 ice certifies in writing to the facility, in a docu-
15 ment signed by a supervisory official of a rank
16 designated by the Secretary of the Treasury, that
17 the information is needed to accomplish the pur-
18 pose of conducting the protective functions of the
19 Secret Service:

20 *Provided, That* no medical care facility, or officer,
21 agent, or employee of such facility, shall disclose to
22 any person that an inquiry made pursuant to this para-
23 graph occurred or that information was disclosed pur-
24 suant to this paragraph and no record of such inquiry
25 or disclosure shall be included as part of the medical

1 information that the facility maintains concerning the
2 individual,

3 (17) of medical information pertaining to a
4 member of the uniformed services in materials belong-
5 ing to any of the uniformed services (as defined in 37
6 U.S.C. 101(3)), to a uniformed services authority,

7 (18) of medical information in materials belonging
8 to a penal or correctional authority, to the penal or
9 correctional authority or to another judicial or execu-
10 tive agency, for purposes of parole, probation, pardon,
11 or commutation of sentence, or judicial review, or to a
12 law enforcement authority for the purpose of investi-
13 gating an offense committed in the facility of the penal
14 or correctional authority,

15 (19) pursuant to a subpoena or court order issued
16 in connection with proceedings before a grand jury,

17 (20) to a person other than a Government author-
18 ity pursuant to compulsory legal process,

19 (21) of medical information in materials belonging
20 to or in the custody of the Veterans' Administration or
21 its contractors or any of the uniformed services, to a
22 Veterans' Administration authority or contractor there-
23 of for the purpose of determining or providing benefits
24 under title 38, United States Code, or

1 (22) to a Government authority, or to a third
2 party potentially liable or responsible to the medical
3 care facility for the cost of providing services to an in-
4 dividual, for the purpose of and to the extent necessary
5 for processing a claim related to medical services re-
6 ceived by an individual.

7 (c) An appropriate United States district court, or any
8 other court of competent jurisdiction, may grant one or more
9 delays of not greater than thirty days each with respect to
10 making a written statement available to the individual under
11 subsection (b) (6) or (7) if the court finds that there is reason
12 to believe that the delay is needed to prevent—

13 (A) endangering the life or physical safety of any
14 person,

15 (B) flight from prosecution,

16 (C) destruction of or tampering with evidence,

17 (D) intimidation of potential witnesses, or

18 (E) otherwise seriously jeopardizing an investiga-
19 tion or official proceeding or unduly delaying a trial or
20 ongoing official proceedings to the same extent as the
21 circumstances in the preceding subparagraphs.

22 An application for delay must be made with reasonable speci-
23 ficity.

24 (d) An authorization by the individual for disclosure re-
25 ferred to in subsection (a) shall—

1 (1) be in writing,

2 (2) be dated,

3 (3) be signed by the individual,

4 (4) make clear that the medical care facility is
5 among those either specifically named or generically
6 designated by the individual as authorized to disclose
7 information concerning the individual,

8 (5) be specific as to the nature of the information
9 authorized to be disclosed,

10 (6) state specifically named or generically desig-
11 nated persons to whom the information may be dis-
12 closed,

13 (7) specifically state the expiration date or event
14 of the authorization.

15 An authorization may be revoked in whole or in part at any
16 time.

17 (e) A medical facility which discloses medical informa-
18 tion that it maintains concerning an individual pursuant to an
19 authorization specified in subsection (d) shall make a copy of
20 the authorization part of the medical information that it
21 maintains concerning the individual.

22 COMPLIANCE WITH THIS ACT AS A CONDITION FOR
23 RECEIPT OF CERTAIN FEDERAL FUNDS

24 SEC. 106. (a) A medical care facility may not continue
25 to participate in or be covered under a program under title

1 XVIII or XIX of the Social Security Act, or to receive funds
2 from appropriations authorized by the Public Health Service
3 Act, title V of the Social Security Act, the Community
4 Mental Health Centers Act, the Comprehensive Alcohol
5 Abuse and Alcoholism Prevention, Treatment, and Rehabili-
6 tation Act of 1970, or the Drug Abuse Office and Treatment
7 Act of 1972, unless the facility provides adequate assurances,
8 and evidence from time to time as required by the Secretary,
9 of its substantial compliance with the requirements of sec-
10 tions 101 through 105.

11 DUTY OF INSTITUTIONAL REVIEW BOARD

12 SEC. 107. If an institutional review board undertakes to
13 determine whether medical information maintained by a
14 medical care facility may be disclosed because the disclosure
15 would not violate section 104 and would meet the require-
16 ments of section 105(b)(5), it shall make that determination in
17 a manner which is neither arbitrary nor capricious.

18 MEDICAL INFORMATION COMPILED SOLELY FOR CIVIL
19 LITIGATION

20 SEC. 108. Sections 101 and 102 of this title shall not
21 apply to any medical information that the facility maintains
22 concerning the individual which is compiled solely in reason-
23 able anticipation of a civil action or proceeding.

1 MEDICAL INFORMATION HELD BY PENAL AND

2 CORRECTIONAL AUTHORITIES

3 SEC. 109. Nothing in this title except section 105 shall
4 apply to medical information in materials belonging to any
5 penal or correctional authority.

6 TITLE II—REQUIREMENTS APPLICABLE TO
7 GOVERNMENT AUTHORITIES

8 ACCESS BY GOVERNMENT AUTHORITIES TO MEDICAL
9 INFORMATION MAINTAINED BY HEALTH CARE
10 PROVIDERS

11 SEC. 201. A Government authority may have access to,
12 or obtain copies of, medical information concerning an indi-
13 vidual maintained by a health care provider only through
14 properly identified persons presenting appropriate evidence of
15 their official status, and only to the extent needed to accom-
16 plish the purpose for which the disclosure is to be made.

17 CONDITIONS FOR ACCESS BY GOVERNMENT AUTHORITIES
18 TO MEDICAL INFORMATION MAINTAINED BY HEALTH
19 CARE PROVIDERS

20 SEC. 202. A Government authority may have access to,
21 or obtain copies of, medical information concerning an indi-
22 vidual maintained by a health care provider only if the infor-
23 mation is reasonably described and—

24 (1) the individual has authorized the disclosure as
25 provided in section 105(d),

1 (2) is needed by a person employed by, an agent
2 of, or responsible to, the health care provider, to carry
3 out his duties,

4 (3) is needed by another health care provider, in
5 connection with health services being provided to the
6 individual,

7 (4) is needed in compelling circumstances which
8 the facility has in good faith determined will affect the
9 health or safety of the individual or another person,

10 (5) is to be used in a biomedical, epidemiologic, or
11 health services research project, if the conditions set
12 forth in section 105(b)(5) are met,

13 (6) is needed—

14 (A) for a public health investigation, for an
15 investigation of activities of the health care pro-
16 vider, or for an audit or evaluation purpose, or

17 (B) to carry out a program under title V,
18 part B of title XI, title XVIII, or title XIX of the
19 Social Security Act, or other program providing
20 payments to, or concerned with activities of, the
21 health care provider, or to conduct an investiga-
22 tion concerning fraud, abuse, or waste under
23 those programs,

1 (7) is reported to a public health authority pursu-
2 ant to a Federal or State law requiring disclosure to a
3 public health authority,

4 (8) is reported to a law enforcement authority,
5 pursuant to a Federal or State law that requires specif-
6 ic types of information to be reported to that authority,

7 (9) reveals only the presence of the individual at
8 the facility at a particular time or the provision of
9 services at a particular time to the individual, his loca-
10 tion, or his general medical condition, if—

11 (A) the individual has not objected to the dis-
12 closure, or

13 (B) the disclosure is pursuant to a legitimate
14 law enforcement inquiry,

15 (10) is sought by a Federal authority pursuant to
16 an administrative summons or subpoena, search war-
17 rant, judicial subpoena, or formal written request, if—

18 (A) the Federal authority has complied with
19 the applicable requirements of sections 203
20 through 206, and

21 (B) the Federal authority certifies in writing
22 to the health care provider that the Federal au-
23 thority has complied with the applicable require-
24 ments of sections 203 through 206,

(11) is sought by a State authority pursuant to an administrative summons or subpoena, search warrant, judicial subpoena, or formal written request, if—

(A) the State authority has complied with the applicable requirements under section 207, and

(B) the State authority certifies in writing to the health care provider that the State authority has complied with the applicable requirements under section 207,

(12) is immediately needed to prevent the imminent danger of—

(A) serious property damage, or

(B) flight to avoid prosecution,

if, before the disclosure or as soon thereafter as practical, the Government authority certifies in writing to the health care provider, in a document signed by a supervisory official of a rank designated by the head of the Government authority, that the information is needed for one of the two reasons specified in this paragraph,

(13) is sought under the Federal Rules of Civil or Criminal Procedure or comparable rules of State courts in connection with litigation to which the Government authority and the individual are parties,

1 (14) is sought pursuant to an administrative sub-
2 pena issued by an administrative law judge or compa-
3 rable State official in an adjudicatory proceeding sub-
4 ject to section 554 of title 5, United States Code, or
5 comparable provisions of State law to which the Gov-
6 ernment authority and the individual are parties,

7 (15)(A) is needed for a purpose of conducting for-
8 eign intelligence or counterintelligence activities by a
9 Federal authority authorized to conduct such activities,
10 if the Federal authority certifies in writing to the
11 health care provider, in a document signed by a super-
12 visory official of a rank designated by the head of the
13 Federal authority, that the information is needed to ac-
14 complish that purpose, or

15 (B) is needed by the Secret Service for the pur-
16 pose of conducting its protective functions, if the
17 Secret Service certifies in writing to the health care
18 provider, in a document signed by a supervisory official
19 of a rank designated by the Secretary of the Treasury,
20 that the information is needed to accomplish that pur-
21 pose:

22 *Provided*, That no health care provider, or associate, employ-
23 ee or agent of such provider, shall disclose to any person that
24 an inquiry made pursuant to this paragraph occurred or that
25 information was disclosed pursuant to this paragraph, and no

1 record of such inquiry or disclosure shall be included as part
2 of the medical information that the provider maintains con-
3 cerning the individual,

4 (16)(A) is in materials belonging to any of the uni-
5 formed services (as defined in 37 U.S.C. 101(3)), and

6 (B) is sought by a uniformed services authority,

7 (17)(A) is in materials belonging to a penal or cor-
8 rectional authority, and

9 (B) is sought by the penal or correctional authori-
10 ty, or by another judicial or executive agency, for pur-
11 poses of parole, probation, pardon, or commutation of
12 sentence, or judicial review, or by a law enforcement
13 authority for the purpose of investigating an offense
14 committed in a facility of the penal or correctional
15 authority,

16 (18) is sought pursuant to a subpoena or court
17 order issued in connection with proceedings before a
18 grand jury,

19 (19) is in materials belonging to the Veterans'
20 Administration or its contractors and is sought by the
21 Veterans' Administration or its contractor or any of
22 the uniformed services for the purpose of determining
23 or providing benefits under title 38, United States
24 Code, or

1 (20) is sought by a Federal Government authority
2 for the purpose of and to the extent necessary for proc-
3 essing a claim related to medical services received by
4 an individual.

5 **FEDERAL ADMINISTRATIVE SUBPENNA AND SUMMONS**

6 **SEC. 203.** A Federal authority may obtain medical in-
7 formation concerning an individual under section 202(10)
8 pursuant to an administrative subpoena or summons otherwise
9 authorized by law only if—

10 (1) there is reason to believe that the records
11 sought are relevant to a legitimate law enforcement
12 inquiry,

13 (2) a copy of the subpoena or summons has been
14 served upon the individual or mailed to his last known
15 address on or before the date on which the subpoena or
16 summons was served on the health care provider to-
17 gether with the following notice which shall state with
18 reasonable specificity the nature of the law enforce-
19 ment inquiry:

20 “Records or information concerning you held by
21 the health care provider named in the attached sub-
22 pena or summons are being sought by this (agency or
23 department) in accordance with the Privacy of Medical
24 Information Act for the following purpose: .

1 If you desire that such records or information not be
2 made available, you must:

3 "1. Fill out the accompanying motion paper
4 and sworn statement or write one of your own,
5 stating that you are the individual whose records
6 are being requested by the Government and either
7 giving the reasons you believe that the records
8 are not relevant to the legitimate law enforcement
9 inquiry stated in this notice or any other legal
10 basis for objecting to the release of the records.

11 "2. File the motion and statement by mailing
12 or delivering them to the clerk of any one of the
13 following United States district courts: .

14 "3. Serve the Government authority the rec-
15 ords by mailing or delivering a copy of your
16 motion and statement to .

17 "4. Be prepared to come to court and pres-
18 ent your position in further detail.

19 "5. You do not need to have a lawyer, al-
20 though you may wish to employ one to represent
21 you and protect your rights.

22 If you do not follow the above procedures, upon the
23 expiration of ten days from the date of service or four-
24 teen days from the date of mailing of this notice, the

1 records or information requested therein will be made
2 available. These records may be transferred to other
3 Government authorities for legitimate law enforcement
4 inquiries, in which event you will be notified after the
5 transfer.”, and

6 (3) ten days have expired from the date of service
7 of the notice or fourteen days have expired from the
8 date of mailing the notice to the individual and within
9 such time period the individual has not filed a sworn
10 statement and motion to quash in an appropriate court,
11 or the challenge provisions of section 209 have been
12 complied with.

13 FEDERAL SEARCH WARRANTS

14 SEC. 204. (a) A Federal authority may obtain medical
15 information concerning an individual under section 202(10)
16 pursuant to a search warrant only if it obtains a search war-
17 rant pursuant to the Federal Rules of Criminal Procedure.

18 (b) No later than ninety days after the Federal authority
19 serves the search warrant, it shall mail to the individual's
20 last known address a copy of the search warrant together
21 with the following notice:

22 “Records or information concerning you held by the
23 health care provider named in the attached search warrant
24 were obtained by this (agency or department) on (date) for

1 the following purpose: . You may have rights
2 under the Privacy of Medical Information Act.”.

3 **FEDERAL JUDICIAL SUBPENA**

4 SEC. 205. A Federal authority may obtain medical in-
5 formation concerning an individual under section 202(10)
6 pursuant to a judicial subpoena only if—

7 (1) such subpoena is authorized by law and there is
8 reason to believe that the records sought are relevant
9 to a legitimate law enforcement inquiry,

10 (2) a copy of the subpoena has been served upon
11 the individual or mailed to his last known address on
12 or before the date on which the subpoena was served on
13 the health care provider together with the following
14 notice which shall state with reasonable specificity the
15 nature of the law enforcement inquiry:

16 “Records or information concerning you which
17 are held by the health care provider named in the at-
18 tached subpoena are being sought by the (agency or de-
19 partment) in accordance with the Privacy of Medical
20 Information Act for the following purpose: .

21 If you desire that such records or information not be
22 made available, you must: .

23 “1. Fill out the accompanying motion paper
24 and sworn statement or write one of your own,
25 stating that you are the individual whose records

1 are being requested by the Government and either
2 giving the reasons you believe that the records
3 are not relevant to the legitimate law enforcement
4 inquiry stated in this notice or any other legal
5 basis for objecting to the release of the records.

6 “2. File the motion and statement by mailing
7 or delivering them to the clerk of the
8 court.

9 “3. Serve the Government authority request-
10 ing the records by mailing or delivering a copy of
11 your motion and statement to .

12 “4. Be prepared to come to court and pres-
13 ent your position in further detail.

14 “5. You do not need to have a lawyer, al-
15 though you may wish to employ one to represent
16 you and protect your rights.

17 If you do not follow the above procedures, upon the
18 expiration of ten days from the date of service or four-
19 teen days from the date of mailing of this notice, the
20 records or information requested therein will be made
21 available. These records may be transferred to other
22 Government authorities for legitimate law enforcement
23 inquiries, in which event you will be notified after the
24 transfer.”, and

(3) ten days have expired from the date of service or fourteen days from the date of mailing of the notice to the individual and within such time period the individual has not filed a sworn statement and motion to quash in an appropriate court, or the challenge provisions of section 209 have been complied with.

FEDERAL FORMAL WRITTEN REQUEST

SEC. 206. A Federal authority may request medical information concerning an individual under section 202(10) pursuant to a formal written request only if—

(1) no administrative summons or subpoena authority reasonably appears to be available to the Federal authority to obtain medical information for the purpose for which such information is sought,

(2) the request is authorized by regulations promulgated by the head of the agency or department,

(3) there is reason to believe that the medical information sought is relevant to a legitimate law enforcement inquiry, and

(4)(A) a copy of the request has been served upon the individual or mailed to his last known address on or before the date on which the request was made to the health care provider together with the following notice which shall state with reasonable specificity the nature of the law enforcement inquiry:

1 “Records or information concerning you held by
2 the health care provider named in the attached request
3 are being sought by this (agency or department) in ac-
4 cordance with the Privacy of Medical Information Act
5 for the following purpose: . If you
6 desire that such records or information not be made
7 available, you must:

8 “1. Fill out the accompanying motion paper
9 and sworn statement or write one of your own,
10 stating that you are the individual whose records
11 are being requested by the Government and either
12 giving the reasons you believe that the records
13 are not relevant to the legitimate law enforcement
14 inquiry stated in this notice or any other legal
15 basis for objecting to the release of the records.

16 “2. File the motion and statement by mailing
17 or delivering them to the clerk of any one of the
18 following United States district courts: .

19 “3. Serve the Government authority request-
20 ing the records by mailing or delivering a copy of
21 your motion and statement to .

22 “4. Be prepared to come to court and pres-
23 ent your position in further detail.

1 “5. You do not need to have a lawyer, al-
2 though you may wish to employ one to represent
3 you and protect your rights.

4 If you do not follow the above procedures, upon the
5 expiration of ten days from the date of service or four-
6 teen days from the date of mailing of this notice, the
7 records or information requested therein may be made
8 available. These records may be transferred to other
9 Government authorities for legitimate law enforcement
10 inquiries, in which event you will be notified after the
11 transfer.”, and

12 (B) ten days have expired from the date of service
13 or fourteen days from the date of mailing of the notice
14 to the individual and within such time period the indi-
15 vidual has not filed a sworn statement and an applica-
16 tion to enjoin the Government authority in an appro-
17 priate court, or the challenge provisions of section 209
18 have been complied with.

19 STATE ADMINISTRATIVE SUMMONS AND SUBPENA,
20 SEARCH WARRANT, JUDICIAL SUBPENA, AND FORMAL
21 WRITTEN REQUEST

22 SEC. 207. A state authority may obtain medical infor-
23 mation concerning an individual under section 202(11) only if
24 the State authority complies with the applicable requirements
25 of sections 203 through 206 as they would apply to a Federal

1 authority, except that, for purposes of this section, references
2 in sections 203 through 206 to a Federal court, procedure, or
3 other matter shall refer to an appropriate State court, proce-
4 dure, or other matter, or, if the State authority so chooses, to
5 the Federal court, procedure, or other matter.

6 **DELAYED NOTICE—PRESERVATION OF RECORDS**

7 **SEC. 208.** (a) Upon application of the Government au-
8 thority, a notice required under section 203(2), 204(b),
9 205(2), 206(4), 207, or 211(b) may be delayed by order of an
10 appropriate court if the presiding judge or magistrate finds
11 that—

12 (1) the investigation being conducted is within the
13 lawful jurisdiction of the Government authority seeking
14 the medical information,

15 (2) there is reason to believe that the medical in-
16 formation being sought is relevant to a legitimate law
17 enforcement inquiry, and

18 (3) there is reason to believe that such notice will
19 result in—

20 (A) endangering the life or physical safety of
21 any person,

22 (B) flight from prosecution,

23 (C) destruction of or tampering with evi-
24 dence,

25 (D) intimidation of potential witnesses, or

1 (E) otherwise seriously jeopardizing an inves-
2 tigation or official proceeding or unduly delaying a
3 trial or ongoing official proceeding to the same
4 extent as the circumstances in the preceding sub-
5 paragraphs.

6 An application for delay must be made with reasonable speci-
7 ficity.

8 (b)(1) If the court makes the findings required in para-
9 graphs (1), (2), and (3) of subsection (a), it shall enter an ex
10 parte order granting the requested delay for a period not to
11 exceed ninety days and shall issue an order prohibiting the
12 health care provider from disclosing that confidential informa-
13 tion has been obtained or that a request for confidential infor-
14 mation has been made, except that, if the court finds that
15 there is reason to believe that such notice may endanger the
16 lives or physical safety of a patient or former patient or group
17 of patients, or any person or group of persons associated with
18 a patient or former patient, the court may specify that the
19 delay be indefinite.

20 (2) Extensions of the delay of notice provided in para-
21 graph (1) of up to ninety days each may be granted by the
22 court upon application, but only in accordance with this sub-
23 section.

24 (3) Upon expiration of the period of delay of notification
25 under paragraph (1) or (2), the individual shall be served with

1 or mailed a copy of the process or request, together with the
2 following notice which shall state with reasonable specificity
3 the nature of the law enforcement inquiry:

4 “Records or information concerning you which are held
5 by the health care provider named in the attached process or
6 request were supplied to or requested by the Government
7 authority named in the process or request on (date). Notifica-
8 tion was withheld pursuant to a determination by the (title of
9 court so ordering) under the Privacy of Medical Information
10 Act that such notice might (state reason). The purpose of the
11 investigation or official proceeding was (state purpose).”.

12 (c) When access to medical information is obtained pur-
13 suant to section 202(12) (emergency access), the Government
14 authority shall, unless a court has authorized delay of notice
15 pursuant to subsections (a) and (b), as soon as practicable
16 after such records are obtained serve upon the individual, or
17 mail by registered or certified mail to his last known address,
18 a copy of the request to the health care provider together
19 with the following notice which shall state with reasonable
20 specificity the nature of the law enforcement inquiry:

21 “Records concerning you held by the health care pro-
22 vider named in the attached request were obtained by
23 (agency or department) under the Privacy of Medical Infor-
24 mation Act on (date) for the following purpose: .

1 Emergency access to such records was obtained on the
2 grounds that (state grounds).”.

3 (d) Any memorandum, affidavit, or other paper filed in
4 connection with a request for delay in notification shall be
5 preserved by the court. Upon petition by the individual to
6 whom such papers pertain, the court may order disclosure of
7 such papers to the petitioner unless the court makes the find-
8 ings required in subsection (a).

9 CHALLENGE PROVISIONS

10 SEC. 209. (a) Within ten days of service or within four-
11 teen days of mailing of a summons, subpoena, or formal writ-
12 ten request, an individual may file a motion to quash the
13 summons or subpoena, or an application to enjoin a Govern-
14 ment authority from obtaining medical information concern-
15 ing him pursuant to the formal written request, with copies
16 served upon the Government authority. No filing fee shall be
17 required. A motion to quash a judicial subpoena shall be filed
18 in the court which issued the subpoena. A motion to quash an
19 administrative summons or subpoena or an application to
20 enjoin a Government authority from obtaining medical infor-
21 mation pursuant to a formal written request, shall be filed in
22 the appropriate court. Such motion or application shall con-
23 tain an affidavit or sworn statement—

24 (1) stating that the applicant believes the health
25 care provider from which the medical information is

1 sought maintains medical information concerning the
2 individual, and

3 (2) stating the applicant's reasons for believing
4 that the medical information sought is not relevant to
5 the legitimate law enforcement inquiry stated by the
6 Government authority in its notice, or that there has
7 not been substantial compliance with the provisions of
8 this title.

9 Service shall be made under this section upon a Government
10 authority by delivering or mailing by registered or certified
11 mail a copy of the papers to the person, office, or department
12 specified in the notice which the individual has received pur-
13 suant to this title. For the purposes of this section, "deliv-
14 ery" has the meaning stated in rule 5(b) of the Federal Rules
15 of Civil Procedure or comparable rules of State Courts.

16 (b) If the court finds that the individual has complied
17 with subsection (a), it shall order the Government authority
18 to file a sworn response, which may be filed in camera if the
19 Government authority includes in its response the reasons
20 which make in camera review appropriate. If the court is
21 unable to determine the motion or application on the basis of
22 the parties' initial allegations and response, the court may
23 conduct such additional proceedings as it deems appropriate.
24 All such proceedings shall be completed and the motion or

1 application decided within seven calendar days of the filing of
2 the Government authority's response.

3 (c) If the court finds that the medical information is
4 medical information concerning that individual, and that
5 there is a demonstrable reason to believe that the law en-
6 forcement inquiry is legitimate, a reasonable belief that the
7 medical information sought is relevant to that inquiry, and
8 that there has been substantial compliance with the provi-
9 sions of this Act, it shall deny the motion or application, and,
10 in the case of an administrative summons or court order other
11 than a search warrant, order such process enforced. If the
12 court finds that the medical information is medical informa-
13 tion concerning that individual, and that there is not a de-
14 monstrable reason to believe that the law enforcement in-
15 quiry is legitimate, or there is not a reasonable belief that the
16 medical information sought is relevant to that inquiry, or
17 there has not been substantial compliance with the provisions
18 of this Act, it shall order the process quashed or shall enjoin
19 the Government authority's formal written request.

20 (d) A court ruling denying a motion or application under
21 this section shall not be deemed a final order and no interloc-
22 utory appeal may be taken therefrom by the individual. An
23 appeal of a ruling denying a motion or application under this
24 section may be taken by the individual (1) within such period
25 of time as provided by law as part of any appeal from a final

1 order in any legal proceeding initiated against him arising out
2 of or based upon the medical information, or (2) within thirty
3 days after a notification that no legal proceeding is contem-
4 plated against him. The Government authority obtaining the
5 medical information shall promptly notify an individual when
6 a determination has been made that no legal proceeding
7 against him is contemplated. After one hundred and eighty
8 days from the denial of the motion or application, if the Gov-
9 ernment authority obtaining the medical information has not
10 initiated such a proceeding, a supervisory official of the Gov-
11 ernment authority shall certify to the appropriate court that
12 no such determination has been made. The court may require
13 that such certifications be made, at reasonable intervals
14 thereafter, until either notification to the individual has oc-
15 curred or a legal proceeding is initiated as described in clause
16 (1).

17 (e) The challenge procedures of this title constitute the
18 sole judicial remedy available to an individual to oppose dis-
19 closure of medical information pursuant to section 202(10).

20 USE OF INFORMATION

21 SEC. 210. (a) Medical information originally obtained
22 under section 202 (10), (11), or (12) may be transferred only
23 to another Government authority, and only if the transferring
24 authority certifies in writing that there is reason to believe
25 that the information is relevant to a legitimate law enforce-

1 ment inquiry within the jurisdiction of the receiving
2 authority.

3 (b) When medical information subject to this Act is
4 transferred pursuant to subsection (a), the transferring au-
5 thority shall, within fourteen days, send to the individual a
6 copy of the certification made pursuant to subsection (a) and
7 the following notice, which shall state the nature of the law
8 enforcement inquiry with reasonable specificity: "Copies of,
9 or information contained in, your medical records lawfully in
10 possession of _____ have been furnished to
11 pursuant to the Privacy of Medical Information Act for the fol-
12 lowing purpose: _____. If you believe that this
13 transfer has not been made to further a legitimate law en-
14 forcement inquiry, you may have legal rights under that
15 Act.".

16 (c) Notwithstanding subsection (b), notice to the individ-
17 ual may be delayed if the transferring authority has obtained
18 a court order delaying notice pursuant to section 208 (a) and
19 (b) and that order is still in effect, or if the receiving authority
20 obtains a court order authorizing a delay in notice pursuant
21 to section 208 (a) and (b). Upon the expiration of any such
22 period of delay, the transferring authority shall serve to the
23 individual the notice specified in subsection (b) above and the
24 authority that obtained the court order authorizing a delay in

1 notice pursuant to section 208 (a) and (b) shall serve to the
2 individual the notice specified in section 208(b).

3 **ADDITIONAL REQUIREMENTS FOR GOVERNMENT**

4 **AUTHORITIES**

5 **SEC. 211.** (a) Within five days of obtaining access to
6 medical information under section 202(12), the Government
7 authority shall file with the appropriate court a signed, sworn
8 statement of a supervisory official of a rank designated by the
9 head of the Government authority setting forth the grounds
10 for the emergency access.

11 (b) Each Federal authority obtaining access to medical
12 information under section 202 (12) or (15) shall compile an
13 annual tabulation of the occasions on which access was ob-
14 tained under those provisions.

15 (c) Unless otherwise provided by law, a Federal authori-
16 ty shall pay to the health care provider assembling or provid-
17 ing medical information concerning an individual under sub-
18 section (b)(11), (b)(13), (b)(16), or (d) of section 105, a fee for
19 reimbursement for such costs as are reasonably necessary
20 and which have been directly incurred in searching for, re-
21 producing, or transporting books, papers, records, or other
22 data required or requested to be produced. The Secretary
23 shall, by regulation, establish the rates and conditions under
24 which such payment shall be made.

1 GRAND JURY INFORMATION

2 SEC. 212. Medical information concerning an individual
3 obtained from a health care provider pursuant to a subpoena
4 issued under the authority of a grand jury—

5 (1) shall be returned and actually presented to the
6 grand jury,

7 (2) shall be used only for the purpose of consider-
8 ing whether to issue an indictment or presentment by
9 the grand jury, or of prosecuting a crime for which
10 that indictment or presentment is issued, or for a pur-
11 pose authorized by rule 6(e) of the Federal Rules of
12 Criminal Procedure or comparable rules of State
13 courts,

14 (3) shall be destroyed or returned to the health
15 care provider if not used for one of the purposes speci-
16 fied in clause (2), and

17 (4) shall not be maintained (and a description of
18 the contents of the information shall not be maintained)
19 by any Government authority other than in the sealed
20 records of the grand jury, unless those records have
21 been used in the prosecution of a crime for which the
22 grand jury issued an indictment of presentment or for a
23 purpose authorized by rule 6(e) of the Federal Rules of
24 Criminal Procedure or comparable rules of State
25 courts.

TITLE III—GENERAL PROVISIONS

OBTAINING MEDICAL INFORMATION THROUGH DECEPTION

SEC. 301. Any person who, under false pretenses, requests or obtains medical information concerning an individual from a health care provider shall be guilty of a misdemeanor and upon conviction thereof shall be fined not more than \$10,000 or imprisoned for not more than one year, or both.

CIVIL SUITS

SEC. 302. (a) Any person aggrieved by—

(1) a violation by a medical care facility of any provision of sections 101 through 105,

(2) a violation by an institutional review board of section 107,

(3) a violation by a Government agency of any provision of section 201, 202, 208, 210, 211, or 212,

(4) the commission of acts which constitute a crime under section 301, or

(5) a violation by a researcher of any provision of section 105(b)(5),

may bring a civil action in any appropriate United States district court, without regard to the amount in controversy, or in any other court of competent jurisdiction. No such action shall be brought later than two years from the date of the discovery of the violation.

(b) A civil action under subsection (a) may be brought—

1 (1) in the case of a violation under paragraph (1)
2 of subsection (a), against the medical care facility,

3 (2) in the case of a violation under paragraph (2)
4 of subsection (a), against the parent entity of the insti-
5 tutional review board,

6 (3) in the case of a violation under paragraph (3)
7 of subsection (a)—

8 (A) against the United States,

9 (B) against a State which has waived its sov-
10 ereign immunity under the Constitution,

11 (C) against an officer or employee of a State
12 which has not waived its sovereign immunity, or

13 (D) against any other Government authority,

14 (4) in the case of the commission of acts under
15 paragraph (4) of subsection (a), against the person or
16 persons who committed the acts, or

17 (5) in the case of a violation by a researcher
18 under paragraph (5) of subsection (a), against the
19 researcher.

20 A violator shall be liable to the aggrieved individual for all
21 actual damages sustained by the individual.

22 (c) In addition to actual damages awarded under subsec-
23 tion (a), any medical care facility, parent entity of an institu-
24 tional review board, government authority, or researcher that
25 violates any provision of section 104 or 105 or title II of this

1 Act shall be liable to the aggrieved individual for such gener-
2 al damages as the court may allow, but not less than \$100
3 nor more than \$10,000. In determining the amount of gener-
4 al damages, the court shall consider, among other relevant
5 factors, the amount of any actual damages awarded and the
6 nature and seriousness of any intangible harm suffered by the
7 individual.

8 (d) Upon application by an aggrieved individual the ap-
9 propriate United States district court or any other court of
10 competent jurisdiction may grant such equitable and declara-
11 tory relief as is necessary to enforce the requirements im-
12 posed under this Act.

13 (e) In a successful action brought under this section, the
14 costs of the action, together with reasonable attorneys' fees
15 as determined by the court, may be awarded in addition to
16 any damages.

17 (f) It shall be a defense to an action brought against a
18 medical care facility or researcher under subsection (a)(1) for
19 a violation of section 104 or 105(a) that an institutional
20 review board determined that the disclosure involved violated
21 neither section 104, nor section 105(a) because of the appli-
22 cability of section 105(b)(5).

23 **SUSPENSION OF FEDERAL STATUTES OF LIMITATIONS**

24 **SEC. 303.** If any individual files a motion or application
25 under this Act which has the effect of delaying the access of

1 a Federal authority to medical information concerning the
2 individual, any applicable statute of limitations shall be
3 deemed to be tolled for the period extending from the date
4 such motion or application was filed until the date upon
5 which the motion or application is decided.

6 DISCLOSURE OF SURVEYS OF COMPLIANCE

7 SEC. 304. (a) Any limitation in section 1106 of the
8 Social Security Act concerning the disclosure of information
9 shall not apply to information (except for medical information
10 concerning an individual) contained in surveys of compliance
11 with the provisions of this part conducted by or for the
12 Secretary.

13 (b) If the Secretary enters into a contract for conducting
14 a survey of compliance with the provisions of this Act, the
15 contract shall require the contractor to make available to the
16 Secretary and for public inspection all information (except
17 medical information concerning an individual) obtained for,
18 and any reports resulting from, that survey.

19 REGULATIONS

20 SEC. 305. The Secretary may prescribe regulations to
21 carry out the provisions of this Act.

22 RECORDS

23 SEC. 306. Each Federal authority that requests access
24 to medical information concerning an individual from a health
25 care provider pursuant to section 202 (10), (12), or (15) shall

1 maintain records describing each such request. Those records
2 shall include the number of requests for medical information
3 made pursuant to each provision of this Act listed in the pre-
4 ceding sentence and the reason for each such request.

5 **AMENDMENTS TO FEDERAL AGENCY PRIVACY PROVISIONS**

6 **SEC. 307.** Section 552a of title 5, United States Code,
7 is amended—

8 (1) in subsection (a)(4), by inserting before the
9 semicolon the following: “, except that, for purposes of
10 subsections (b) and (d), paragraphs (3)(C), (4)(D), and
11 (8) of subsection (e), and paragraphs (3) and (4) of sub-
12 section (f), the term does not include medical informa-
13 tion concerning an individual (as defined by section
14 310(1) of the Privacy of Medical Information Act)
15 maintained by a medical care facility (as defined by
16 section 310(2) of that Act)“, and

17 (2) in subsection (i)(1), by striking out “or by rules
18 or regulations established thereunder” and inserting in-
19 stead “or by the Privacy of Medical Information Act,
20 or by rules or regulations established under that Act or
21 this section”.

22 **EFFECT ON OTHER LAWS**

23 **SEC. 308.** This part shall override State and other Fed-
24 eral laws only to the extent that those laws are inconsistent
25 with the provisions of this part. Nothing in this Act shall

1 enlarge or restrict any rights of a health care provider to
 2 challenge requests for records made by a Federal authority
 3 under existing law.

4 CONTINUED APPLICABILITY OF ACT

5 SEC. 309. If a facility ceases to be a medical care facili-
 6 ty, the provisions of this Act shall continue to apply to medi-
 7 cal information concerning an individual maintained by the
 8 facility before it ceased to be a medical care facility.

9 DEFINITIONS AND RELATED MATTERS

10 SEC. 310. For purposes of this Act—

11 (1) “medical information” concerning an individu-
 12 al means materials that—

13 (A)(i) contain information relating to the
 14 health, examination, care, or treatment of the in-
 15 dividual, or (ii) are to be added to such materials
 16 under provisions of this Act, and

17 (B) are in a form enabling the individual to
 18 be identified,

19 (2) “medical care facility” means any facility (in-
 20 cluding any Federal facility, but excluding any State or
 21 local government facility that does not receive any
 22 Federal funds after the effective date of this Act) that
 23 is primarily engaged in providing—

24 (A) to inpatients (i) diagnostic services and
 25 therapeutic services for medical diagnosis, treat-

1 ment, and care of injured, disabled, or sick indi-
2 viduals, or (ii) rehabilitation services for the reha-
3 bilitation of injured, disabled, or sick individuals,

4 (B) health-related services to individuals in
5 the facility who because of their mental or physi-
6 cal condition require such services (above the
7 level of room and board), or

8 (C) health-related services to outpatients, if
9 (i) the facility is receiving funds from appropri-
10 ations authorized by the Public Health Service
11 Act, title V of the Social Security Act, the Com-
12 munity Mental Health Centers Act, the Compre-
13 hensive Alcoholism Abuse and Alcoholism Pre-
14 vention, Treatment, and Rehabilitation Act of
15 1970, or the Drug Abuse Office and Treatment
16 Act of 1972, and (ii) the facility is made subject
17 to the provisions of this Act by regulations of the
18 Secretary,

19 (3) “health care provider” means any—

20 (A) medical care facility, and

21 (B) any person or other entity that provides
22 health services to individuals,

23 (4) “Federal authority” means any agency or de-
24 partment of the United States, or any officer, employ-

1 ee, or agent thereof, but does not include the
2 Congress,

3 (5) "State" includes the District of Columbia and
4 each United States territory or possession,

5 (6) "State authority" means any agency or de-
6 partment of any State, or of any local unit of govern-
7 ment of any State, or any officer, employee, or agent
8 thereof, but does not include a State legislature,

9 (7) "Government authority" means any Federal
10 or State authority,

11 (8) "law enforcement inquiry" means a lawful in-
12 vestigation or official proceeding inquiring into a viola-
13 tion of, or failure to comply with, any criminal or civil
14 statute or any regulation, rule, or order issued pursu-
15 ant thereto,

16 (9) "Secretary" means the Secretary of Health,
17 Education, and Welfare, except that as to matters per-
18 taining to a medical care facility of, or as to matters
19 pertaining to services performed for, the Veterans' Ad-
20 ministration or the Department of Defense, "Secre-
21 tary" means the Administrator of the Veterans' Affairs
22 and the Secretary of Defense, respectively,

23 (10) the rights of, and obligations with respect to,
24 an individual, shall be exercised by, and discharged
25 through, respectively—

1 (A) in the case of an individual under eight-
2 een years of age, a parent or guardian of the indi-
3 vidual, except (i) in those circumstances, as pre-
4 scribed in regulations of the Secretary, in which it
5 is in the interest of the individual to exercise his
6 own rights and to have obligations with respect to
7 him discharged through him, or (ii) as otherwise
8 provided in subparagraph (B), and

9 (B) in the case of an incompetent or de-
10 ceased individual (or of an incompetent parent or
11 guardian under subparagraph (A)), or of an indi-
12 vidual (or a parent or guardian under subclause
13 (A)) suffering from a health condition that pre-
14 vents the individual (or parent or guardian) from
15 acting effectively on the individual's behalf, an ap-
16 propriate person (as defined by the Secretary),

17 (11) a requirement to provide a notification or
18 other matter to a person shall be satisfied if the notifi-
19 cation or matter is sent to the last known address of
20 the person,

21 (12) "arbitrary" and "capricious" have the mean-
22 ings of those terms under section 706(2)(A) of title 5,
23 United States Code, and

24 (13) "institutional review board" means—

1 (A) such a board under section 474(a) of the
2 Public Health Service Act, or

3 (B) a similar board which meets such re-
4 quirements as the Secretary may specify.

5 EFFECTIVE DATE

6 SEC. 311. Section 105 and title II, with respect to dis-
7 closure to State authorities, are effective two years after the
8 enactment of this Act. This Act is otherwise effective one
9 year after its enactment.

To protect the privacy of medical information maintained by medical care facilities, to amend section 552a of title 5, United States Code, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

NOVEMBER 16, 1979

Mr. PREYER (for himself, Mr. KINDNESS, Mr. BROOKS, Mr. HORTON, Mr. RANGEL, Mr. CARTER, Mr. KOSTMAYER, Mr. GOLDWATER, Mr. CORMAN, Mr. OBERSTAR, Mr. KILDEE, Mr. LaFALCE, Mr. MATTOX, Mr. STOCKMAN, and Mrs. FENWICK) introduced the following bill; which was referred jointly to the Committees on Government Operations, Interstate and Foreign Commerce, and Ways and Means

A BILL

To protect the privacy of medical information maintained by medical care facilities, to amend section 552a of title 5, United States Code, and for other purposes.

Be it enacted by the Senate and House of Representa-
tives of the United States of America in Congress assembled,

3 SHORT TITLE

SECTION 1. This Act may be cited as the “Federal
Privacy of Medical Information Act”.

TABLE OF CONTENTS

- Sec. 1. Short title.
- Sec. 2. Findings and purposes.

TITLE I—PRIVACY OF MEDICAL INFORMATION

PART A—DEFINITIONS, EFFECT ON OTHER LAWS, AND RIGHTS OF MINORS AND INCOMPETENTS

- Sec. 101. Definitions.
- Sec. 102. Effect on other laws.
- Sec. 103. Rights of incompetents.
- Sec. 104. Rights of minors.

PART B—RIGHTS OF INSPECTION, AMENDMENT, AND NOTICE, AND AUTHORIZED DISCLOSURE

- Sec. 111. Inspection of medical information.
- Sec. 112. Amendment of medical information.
- Sec. 113. Notice of information practices.
- Sec. 114. Disclosure of medical information.
- Sec. 115. Authorization for disclosure of medical information.

PART C—DISCLOSURE OF MEDICAL INFORMATION WITHOUT SPECIFIC AUTHORIZATION

- Sec. 120. Right of medical care facilities to refuse disclosures.
- Sec. 121. Employee use.
- Sec. 122. Consultation.
- Sec. 123. Admission and health status information.
- Sec. 124. Health research.
- Sec. 125. Audit.
- Sec. 126. Health and safety.
- Sec. 127. Legally required reporting.
- Sec. 128. Secret service or foreign intelligence.
- Sec. 129. Next of kin.
- Sec. 130. Law enforcement functions.
- Sec. 131. Judicial and administrative proceedings.
- Sec. 132. Subpenas, summons, warrants, and search warrants.
- Sec. 133. Federal medical care facilities.
- Sec. 134. Restrictions on use of medical information by Federal grand juries.

PART D—ACCESS PROCEDURES, CHALLENGE RIGHTS, AND REPORTING

- Sec. 141. Access procedures for law enforcement summonses, subpenas, warrants, and search warrants.
- Sec. 142. Challenge procedures for law enforcement summonses and subpenas.
- Sec. 143. Access and challenge procedures for other summonses and subpenas.
- Sec. 144. Construction of part; suspension of statute of limitations.
- Sec. 145. Reports.

PART E—ENFORCEMENT

Sec. 151. Criminal penalty for obtaining medical information through false pretenses or theft.

Sec. 152. Civil suits.

Sec. 153. Responsibilities of Secretary.

TITLE II—AMENDMENT TO TITLE 5, UNITED STATES CODE

Sec. 201. Amendment to title 5, United States Code.

TITLE III—TRANSITION; EFFECTIVE DATES

Sec. 301. Continued applicability of Act.

Sec. 302. Effective dates and promulgation of regulations.

FINDINGS AND PURPOSES

SEC. 2. (a) Congress finds that—

(1)(A) the right to privacy is a personal and fundamental right protected by the Constitution of the United States,

(B) the collection, maintenance, use, and dissemination of medical information can threaten a patient's right to privacy,

(C) medical information about a patient is disclosed by medical care facilities without the knowledge or consent of the patient for purposes unrelated to the provision of medical services to the patient,

(D) disclosure of medical information about a patient can affect the patient's ability to obtain employment, education, insurance, credit, and other necessities,

1 (E) in order to prevent misuse of medical informa-
2 tion, a patient must be able to exercise more direct
3 control over medical information about the patient, and

4 (F) a patient's right to privacy must be balanced
5 against the legitimate needs of public and private orga-
6 nizations for individually identifiable medical informa-
7 tion in performing law enforcement, public health,
8 medical research, health planning, fiscal, and other im-
9 portant functions; and

10 (2)(A) the Federal Government is playing an in-
11 creasingly important role in the provision, payment,
12 and regulation of medical care,

13 (B) due to the large number of patients who
14 travel in interstate commerce seeking medical care, the
15 large volume of medical information sent in interstate
16 commerce, and the complex and interrelated nature of
17 the modern medical care system, all medical care facil-
18 ities affect interstate commerce,

19 (C) violations of the confidentiality of medical in-
20 formation as found by the Congress and by the Privacy
21 Protection Study Commission are problems that re-
22 quire national solutions, and

23 (D) there is a need for Federal statutory protec-
24 tion of the privacy of medical information collected and
25 maintained by medical care facilities.

(b) The purposes of this Act are—

(1) to establish procedures allowing patients to inspect and amend medical information about them;

(2) to define the circumstances under which individually identifiable medical information may be disclosed with, or without, the consent of the patient; and

(3) to make it a crime to request or obtain medical information from medical care facilities under false pretenses.

TITLE I—PRIVACY OF MEDICAL INFORMATION

PART A—DEFINITIONS, EFFECT ON OTHER LAW, AND RIGHTS OF MINORS AND INCOMPETENTS

DEFINITIONS

SEC. 101. For purposes of this Act:

(1) The term “accounting” means, with respect to the disclosure of medical information maintained by a medical care facility, the recording, as part of such information, of (A) the date, nature, and purpose of the disclosure, and (B) the name and business address of the person to whom the disclosure was made.

(2) The term “aggravated property destruction” means damage to property (with a value in excess of \$500) which causes a significant interruption or impairment of its function.

6

1 (3) The term “audit” means an assessment, eval-
2 uation, determination, or investigation relating to—

3 (A) the effectiveness of, compliance with, or
4 applicability of legal, fiscal, medical, or scientific
5 standards or aspects of performance;

6 (B) the licensing, accreditation, or certifica-
7 tion of medical care facilities or medical care pro-
8 fessionals; or

9 (C) medical peer review;
10 conducted by a representative of a public or private or-
11 ganization or government authority, including the Joint
12 Commission on Accreditation of Hospitals and a Pro-
13 fessional Standards Review Organization.

14 (4) The term “employee” means, with respect to
15 a medical care facility or person, an individual who is
16 employed by, responsible to, affiliated with, or perform-
17 ing a function on behalf of, the facility or person, and
18 includes, with respect to a medical care facility, a stu-
19 dent or faculty member of a health professional school
20 affiliated with the facility.

21 (5) The term “government authority” means any
22 entity (including a legislative entity)—

23 (A) of the United States, or of any territory
24 or possession thereof, or

1 (B) of a State or political subdivision therein,
2 or any officer, employee, or agent thereof.

3 (6) The term “health research project” means a
4 biomedical, epidemiologic, or health services research
5 project or a health statistics project.

6 (7)(A) The term “institutional review board”
7 means—

8 (i) an institutional review board established
9 in accordance with regulations of the Secretary
10 under section 474 of the Public Health Service
11 Act,

12 (ii) a similar board established under regula-
13 tions of another Federal Government authority, or

14 (iii) a similar board which meets such re-
15 quirements as the Secretary may specify.

16 (B) The term “appropriate institutional review
17 board” means, with respect to a health research proj-
18 ect intending to use medical information maintained by
19 a facility or researcher, (i) the institutional review
20 board for the organization sponsoring the project, (ii)
21 the institutional review board for the facility or re-
22 searcher, (iii) the institutional review board for another
23 medical facility or institution which maintains medical
24 information also intended to be used in the project, or
25 (iv) an institutional review board established or desig-

1 nated by the Secretary in accordance with section
2 124(c).

3 (8) The term “law enforcement inquiry” means a
4 lawful investigation or official proceeding inquiring into
5 a specific violation of, or failure to comply with, any
6 criminal or civil statute or any regulation, rule, or
7 order issued pursuant thereto.

8 (9) The term “medical care facility” means—

9 (A) a hospital or skilled nursing facility,

10 (B) an intermediate care facility certified by
11 a State agency for participation in a program
12 under title XIX of the Social Security Act,

13 (C) an intermediate care facility, outpatient
14 clinic, or ambulatory care facility operated by a
15 Federal Government authority, or

16 (D) an outpatient clinic or ambulatory care
17 facility receiving funds from a Federal Govern-
18 ment authority under a grant or contract under
19 the Public Health Service Act, title V of the So-
20 cial Security Act, the Community Mental Health
21 Centers Act, the Comprehensive Alcohol Abuse
22 and Alcoholism Prevention, Treatment, and Reha-
23 bilitation Act of 1970, or the Drug Abuse Office
24 and Treatment Act of 1972, if the clinic or facil-

1 ity is made subject to the provisions of this Act
2 by regulation of the Secretary.

3 Such term does not include any such medical facility
4 located outside the United States or which primarily
5 serves inmates or residents of a prison, jail, or other
6 penal or correctional facility.

7 (10) The term “medical information” means any
8 material that—

9 (A)(i) contains information relating to the
10 health, examination, care, or treatment of a pa-
11 tient, or (ii) is to be added to such material under
12 the provisions of this title, and

13 (B) is in a form enabling the patient to be
14 identified.

15 (11) The term “patient” means a living
16 individual.

17 (12) The term “Secretary” means the Secretary
18 of Health and Human Services.

19 (13) The term “State” includes the District of
20 Columbia and the Commonwealth of Puerto Rico.

21 EFFECT ON OTHER LAWS

22 SEC. 102. (a) No law of any State, or political subdivi-
23 sion thereof, may authorize or compel the disclosure of medi-
24 cal information which is prohibited under this title.

25 (b) This title does not supersede—

1 (1) any restriction on the disclosure or use of
2 medical information under (A) section 333 of the Com-
3 prehensive Alcohol Abuse and Alcoholism Prevention,
4 Treatment and Rehabilitation Act of 1970, (B) section
5 408 of the Drug Abuse Office and Treatment Act of
6 1972, or (C) section 1166 of the Social Security Act;

7 (2) any other such restriction of Federal, State, or
8 local law on disclosure or use of medical information
9 relating to alcohol or drug abuse, or examination, care,
10 or treatment for such abuse; or

11 (3) any restriction of Federal, State, or local law
12 on inspection of or disclosure of medical information re-
13 lating to psychiatric, psychological, or mental health
14 examination, care, or treatment.

15 (c)(1) A State may prohibit disclosure of medical infor-
16 mation otherwise permitted to be disclosed under part C of
17 this title.

18 (2) Nothing in this title shall be construed to make any
19 medical care facility of a Federal Government authority or
20 any Federal agency subject to any State or local law not
21 otherwise applicable.

22 (d) The fact that this Act may permit medical informa-
23 tion to be disclosed by a medical care facility shall not in any
24 way abridge or destroy the confidential or privileged charac-

1 ter of the information, except for the purpose for which the
2 disclosure was made.

3 RIGHTS OF INCOMPETENTS

4 SEC. 103. (a) The rights of a patient under this title
5 shall be exercised and discharged in the best interests of the
6 patient through an authorized legal representative of the pa-
7 tient, if the patient has been declared to be incompetent by a
8 court of competent jurisdiction.

9 (b) If a medical care facility determines that a patient,
10 who has not been declared to be incompetent by a court of
11 competent jurisdiction, suffers from a medical condition that
12 prevents the patient from acting knowingly or effectively on
13 the patient's own behalf, the rights of the patient to authorize
14 disclosure under section 115 shall be exercised and dis-
15 charged in the best interests of the patient by the medical
16 care facility or, at the election of the facility, the patient's
17 next of kin.

18 RIGHTS OF MINORS

19 SEC. 104. (a) Except as provided in section 103, in the
20 case of a patient—

21 (1) who is fifteen years of age or older, all rights
22 of the patient shall be exercised by the patient; or

23 (2) who, acting alone, has the legal capacity to
24 apply for and obtain a type of medical examination,
25 care, or treatment and who has sought such examina-

1 tion, care, or treatment, the patient shall exercise all
2 rights of a patient under this title with respect to medi-
3 cal information relating to that examination, care, or
4 treatment.

5 (b) Except as provided in subsection (a)(2), with respect
6 to a patient who is—

7 (1) under twelve years of age, all the patient's
8 rights under this title shall be exercised through the
9 parent or legal guardian of the patient; or

10 (2) twelve, thirteen, or fourteen years of age, the
11 right of inspection (under section 111), the right of
12 amendment (under section 112), and the right to au-
13 thorize disclosure of medical information (under section
14 115) of the patient may be exercised either by the pa-
15 tient or by the parent or legal guardian of the patient.

16 PART B—RIGHTS OF INSPECTION, CORRECTION, AND
17 NOTICE, AND AUTHORIZED DISCLOSURE

18 INSPECTION OF MEDICAL INFORMATION

19 SEC. 111. (a)(1) Except as provided under subsection
20 (b), a medical care facility shall permit a patient to inspect
21 any medical information that the facility maintains about the
22 patient, and shall permit the patient to have a copy of the
23 information. The patient may designate in writing another
24 individual to inspect, or to have a copy of, the information on
25 behalf of the patient and to accompany the patient during the

1 inspection. When a patient or other individual inspects or
2 obtains a copy of medical information under this subsection,
3 the facility may offer to explain or interpret the information.

4 (2) Except as otherwise specifically provided by law, a
5 medical care facility may—

6 (A) require a written request for the inspection
7 and copying of medical information under this section;

8 (B) not charge a fee for permitting inspection of
9 information under this section; and

10 (C) charge a reasonable fee (no greater than the
11 copying fee imposed on third-party payers) for provid-
12 ing a copy of medical information under this section.

13 (3) A medical care facility shall comply with or deny a
14 request for inspection or copying of medical information
15 under this section within the period of thirty days (or such
16 shorter period as may otherwise be provided by law) begin-
17 ning on the date it receives the request.

18 (b)(1) A medical care facility is not required by this sec-
19 tion to permit inspection or copying of information if—

20 (A) in the exercise of reasonable medical judg-
21 ment, the facility determines that inspection or copying
22 of the information would cause sufficient harm to the
23 patient so as to outweigh the desirability of permitting
24 access;

1 (B)(i) the information consists of psychiatric, psy-
2 chological, or mental health treatment notes, and (ii)
3 the facility does not permit disclosure of the notes to
4 any person not engaged in treatment of the patient ex-
5 cept (I) with the patient's authorization or (II) under
6 compulsion of law;

7 (C) the information relates to psychiatric, psy-
8 chological, or mental health examination, care, or
9 treatment—

10 (i) and relates to an individual other than the
11 patient,

12 (ii) the disclosure of which would constitute a
13 danger to the physical safety of any individual, or

14 (iii) and identifies or could reasonably lead to
15 the identification of an individual who is a con-
16 fidential source of information to a health care
17 provider;

18 (D) the information is (i) used by the facility solely
19 for administrative purposes and not in the examination,
20 care, or treatment of the patient, and (ii) is not dis-
21 closed outside the facility;

22 (E) the information duplicates information availa-
23 ble for inspection under subsection (a); or

1 (F) the information is compiled solely in reason-
2 able anticipation of a civil action or proceeding or for
3 use in such an action or proceeding.

4 (2) If information is withheld under paragraph (1)(A),
5 the facility shall permit the information to be inspected and
6 copied by a person, selected by the patient, who is (A) a
7 licensed or certified health professional, (B) an attorney, (C) a
8 family member, or (D) other person permitted to be designat-
9 ed under State law. If inspection or copying of medical infor-
10 mation by the family member selected by the patient would
11 cause sufficient harm to the patient or to a family member so
12 as to outweigh the desirability of permitting access, the facili-
13 ty is not required to permit access by the family member, but
14 the facility shall permit the patient to select another person
15 in accordance with this paragraph.

16 (3) If a facility denies a request for inspection or copying
17 under this section, the facility shall provide the patient (or
18 patient's designated representative) with a written statement
19 of the reasons for the denial.

20 AMENDMENT OF MEDICAL INFORMATION

21 SEC. 112. (a) In the case of a medical care facility that
22 maintains medical information about a patient, if the patient
23 requests in writing that the facility correct or supplement the
24 medical information the facility shall, within the period of
25 forty-five days (or such shorter period as may otherwise be

1 provided under State law) beginning on the date it receives
2 the request, either—

3 (1)(A) make the amendment requested; (B) inform
4 the patient of the amendment that has been made; and
5 (C) inform any person who is identified by the patient,
6 who is not an employee of the facility, and to whom
7 the unamended portion of the information was previ-
8 ously disclosed of the amendment that has been made;
9 or

10 (2) inform the patient of (A) the reasons for its re-
11 fusals to make the amendment, (B) any procedures for
12 further review of the refusal, and (C) the patient's right
13 to file with the facility a concise statement setting
14 forth the requested amendment and the patient's rea-
15 sons for disagreeing with the refusal of the facility.

16 After a patient has filed a statement of disagreement, the
17 facility, in any subsequent disclosure of the disputed portion
18 of the information, shall include a copy of the patient's state-
19 ment and may include a concise statement of the facility's
20 reasons for not making the requested amendment.

21 (b) Subsection (a) shall not be construed to require a
22 medical care facility—

23 (1) to conduct a formal, informal, or other hearing
24 or proceeding concerning a request for an amendment
25 to medical information it maintains, or

1 (2) to erase or otherwise delete any medical infor-
2 mation it determines to be incorrect,
3 and, for purposes of such subsection, a correction is deemed
4 to have been made to medical information where incorrect
5 information is clearly marked as incorrect and supplementary
6 correct information is made part of the medical information
7 about the patient.

8 (c) For purposes of this section, the term "amendment"
9 includes correction and supplementation.

10 NOTICE OF INFORMATION PRACTICES

11 SEC. 113. (a) A medical care facility shall prepare a
12 written notice of information practices describing—

13 (1) the disclosures of medical information that the
14 facility may make without the written authorization of
15 the patient;

16 (2) the rights and procedures under this title, in-
17 cluding the right to inspect and copy medical informa-
18 tion and the right to seek amendments to medical
19 information, and the procedures for authorizing dislo-
20 sures of medical information and for revoking such
21 authorizations; and

22 (3) the procedures established by the facility for
23 the exercise of these rights.

24 (b) A medical care facility shall, upon request, provide
25 any person with a copy of the facility's notice of information

1 practices (described in subsection (a)) and shall post in con-
2 spicuous places in the facility such notice or a statement of
3 availability of such notice and otherwise make reasonable ef-
4 forts to inform patients (and prospective patients) of the fa-
5 cility of the existence and availability of such notice.

6 DISCLOSURE OF MEDICAL INFORMATION

7 SEC. 114. A medical care facility—

8 (1) may not disclose medical information about a
9 patient other than to the patient or the patient's desig-
10 nated representative (under section 111) unless either
11 (A) the patient has authorized the disclosure under sec-
12 tion 115, or (B) the disclosure is permitted under part
13 C without such an authorization;

14 (2) may not disclose medical information to any
15 person unless the person is properly identified; and

16 (3) shall, in the case of disclosure of medical infor-
17 mation made—

18 (A) pursuant to an authorization described in
19 section 115, limit the disclosure to the information
20 authorized to be disclosed, or

21 (B) without such an authorization, limit the
22 disclosure to the information reasonably needed to
23 accomplish the purpose for which the disclosure is
24 made.

1 For purposes of paragraph (3)(B), a facility may rely on a
2 written certification, by the person seeking medical informa-
3 tion, stating the purpose for which the information is being
4 sought and that the information is reasonably necessary to
5 accomplish that purpose.

AUTHORIZATION FOR DISCLOSURE OF MEDICAL
INFORMATION

8 SEC. 115. (a) For purposes of this title, a patient has
9 authorized disclosure to a person of medical information
10 maintained by a medical care facility only if—

11 (1) the authorization is (A) in writing, (B) dated,
12 and (C) signed by the patient;

13 (2) the facility is specifically named or generically
14 described in the authorization as authorized to disclose
15 such information;

(3) the person to whom the information is to be disclosed is specifically named or generically described in the authorization as a person to whom such information may be disclosed;

(4) the information to be disclosed is described in
the authorization; and

(5) the disclosure occurs before the date or event (if any), specified in the authorization, upon which the authorization expires.

1 A State, or political subdivision therein, or a medical care
2 facility may impose additional requirements for authorizations
3 by patients of disclosures.

4 (b) A patient in writing may revoke or amend an author-
5 ization, in whole or in part, at any time, except when dislo-
6 sure of medical information has been authorized to permit
7 validation of expenditures for medical services or based on
8 medical condition by a government authority or when action
9 has been taken in reliance on the authorization.

10 (c) A medical care facility that discloses medical infor-
11 mation about a patient pursuant to this section shall maintain
12 a copy of the authorization as part of the medical information
13 about the patient.

14 PART C—DISCLOSURE OF MEDICAL INFORMATION

15 WITHOUT SPECIFIC AUTHORIZATION

16 RIGHT OF MEDICAL CARE FACILITIES TO REFUSE

17 DISCLOSURES

18 SEC. 120. Except as provided in section 111, nothing in
19 this Act shall be construed to require a medical care facility
20 to disclose medical information not otherwise required to be
21 disclosed by law.

22 EMPLOYEE USE

23 SEC. 121. (a) A medical care facility may disclose medi-
24 cal information it maintains about a patient, without the au-
25 thorization described in section 115(a), if the disclosure is to

1 an employee (as defined in section 101(4)) of the facility who
2 has a need for the medical information in the performance of
3 his duties.

4 (b) Medical information disclosed under this section shall
5 not be further disclosed by an employee except in accordance
6 with this title.

7 CONSULTATION

8 SEC. 122. (a) A medical care facility may disclose medi-
9 cal information it maintains about a patient, without the au-
10 thorization described in section 115(a), if the disclosure is to
11 a medical care professional who will use the information in
12 connection with examination, care, or treatment of a specific
13 patient.

14 (b) Medical information disclosed by a medical care fa-
15 cility under this section shall not be further disclosed except
16 where required by law or necessary to fulfill the purpose for
17 which the information was obtained.

18 ADMISSION AND HEALTH STATUS INFORMATION

19 SEC. 123. A medical care facility may disclose medical
20 information it maintains about a patient, without the authori-
21 zation described in section 115(a), if the disclosure only re-
22 veals the presence of the patient at the facility, his location in
23 the facility, and his general condition, and—

24 (1) the patient has not objected in writing to the
25 disclosure, and

1 mines that there is an adequate health or research jus-
2 tification for retention of such identifiers;

3 (2) not disclose in any public report such medical
4 information that would enable patients to be identified;
5 and

6 (3) not further use or disclose such medical infor-
7 mation in a manner that would enable patients to be
8 identified, except, if not otherwise prohibited by law—

9 (A) for disclosure to an employee of the per-
10 son who has a need for the information in per-
11 forming his duties under the project,

12 (B) in emergency circumstances affecting the
13 health or safety of any person or involving immi-
14 nent danger of aggravated property destruction,

15 (C) for use in another health research proj-
16 ect, under the same conditions and subject to the
17 same restrictions on use and disclosure applicable
18 under this subsection to the original project,

19 (D) for disclosure to a properly identified
20 person for the purpose of an audit related to the
21 project, if information that would enable patients
22 to be identified is removed or destroyed at the
23 earliest opportunity consistent with the purpose of
24 the audit, or

25 (E) when required by law.

1 (c) If a person conducting a health research project is
2 unable to obtain review by an institutional review board of
3 the project for purposes of this section, the Secretary, upon
4 application of the person, may establish an institutional re-
5 view board or may designate any existing institutional review
6 board to review the project.

7 AUDIT

8 SEC. 125. (a) A medical care facility may disclose medi-
9 cal information it maintains about a patient, without the au-
10 thorization described in section 115(a), for purposes of an
11 audit (as defined in section 101(3)).

12 (b) Any person who obtains medical information pursu-
13 ant to subsection (a)—

14 (1) shall remove or destroy, at the earliest oppor-
15 tunity consistent with the purpose of the audit, infor-
16 mation that would enable patients to be identified;

17 (2) shall not disclose in any public report medical
18 information that would enable patients to be identified;
19 and

20 (3) may (unless otherwise prohibited by law) fur-
21 ther use or disclose medical information in a manner
22 that would enable patients to be identified only—

23 (A) for disclosure to an employee of the enti-
24 ty conducting the audit who has a need for the
25 information in performing his duties under the

1 audit or to the person for whom the audit is being
2 conducted,

3 (B) in emergency circumstances affecting the
4 health or safety of any person or involving immi-
5 nent danger of aggravated property destruction,

6 (C) when required by law,

7 (D) for use in a related audit subject to the
8 restrictions on use and disclosure set forth in this
9 subsection, and

10 (E) for use in an administrative, civil, or
11 criminal action or investigation, subject to the re-
12 strictions on use and disclosure set forth in sub-
13 section (c).

14 (c) No medical information about a patient disclosed by
15 a medical care facility under this section may be used in, or
16 disclosed for, any administrative, civil, or criminal action or
17 investigation directed against the patient except in an action
18 or investigation arising out of and directly related to the pro-
19 gram being audited.

20 HEALTH AND SAFETY

21 SEC. 126. (a) A medical care facility may disclose medi-
22 cal information it maintains about a patient, without the au-
23 thorization described in section 115(a), if the disclosure is
24 based on a good faith belief by the employees of the facility
25 that the information is needed—

1 (1) to assist in the identification of a dead person,

2 or

3 (2) to alleviate emergency circumstances—

4 (A) affecting the health or safety of any per-

5 son, or

6 (B) involving imminent danger of aggravated

7 property destruction (as defined in section 101(2)),

8 and the facility maintains an accounting (as defined in

9 section 101(1)) of the disclosure.

10 (b) Medical information disclosed by a medical care fa-

11 cility under this section shall not be further disclosed except,

12 if not otherwise prohibited by law, where necessary to fulfill

13 the purpose for which the information was obtained.

14 **LEGALLY REQUIRED REPORTING**

15 **SEC. 127. (a)** A medical care facility may disclose medi-

16 cal information it maintains about a patient, without the au-

17 thorization described in section 115(a), if the disclosure is—

18 (1) pursuant to a law requiring the reporting of—

19 (A) specific medical information to public

20 health authorities,

21 (B) child abuse and neglect information, or

22 (C) specific medical information to law en-

23 forcement authorities;

(2) of information described in paragraph (1) and the medical care facility is operated by a Federal agency; or

(3) directed by a court in connection with a court-ordered examination of a patient.

(b) Medical information disclosed by a medical care facility under this section shall not be further disclosed except, if not otherwise prohibited by law, where necessary to fulfill the purpose for which the information was obtained, or for a purpose, and subject to the conditions, specified in sections 124 and 125.

SECRET SERVICE OR FOREIGN INTELLIGENCE

SEC. 128. (a) A medical care facility may disclose medical information it maintains about a patient, without the authorization described in section 115(a), if the disclosure is—

(1) to—

(A) the United States Secret Service for the purpose of conducting its protective functions under section 3056 of title 18, United States Code (relating to Secret Service powers), under section 202 of title 3, United States Code (relating to the Executive Protective Service), or under Public Law 90-331 (relating to Secret Service protection of Presidential and Vice Presidential candidates),

1 (B) a Federal Government authority author-
2 ized by statute or executive order to conduct for-
3 eign intelligence or counterintelligence activities
4 for the purpose of conducting such activities; and
5 (2) the government authority seeking the disclo-
6 sure provides the facility with a written certification
7 that—

8 (A) is signed by a supervisory official of a
9 rank designated by the head of the government
10 authority,

11 (B) specifies the information requested, and

12 (C) states that the information is needed for
13 a lawful purpose under this section.

14 If medical information is sought under paragraph (1)(B) about
15 a patient who is a citizen of the United States or an alien
16 lawfully admitted to the United States for permanent resi-
17 dence, a government authority may not make the certifica-
18 tion described in paragraph (2) unless the Attorney General
19 has made a finding that there are reasonable grounds to be-
20 lieve that the patient is an agent of a foreign power (as de-
21 fined in section 101(b) of the Foreign Intelligence Surveil-
22 lance Act of 1978 (50 U.S.C. 1801(b)).

23 (b) No medical care facility, or employee of the facility,
24 shall disclose to any person that a government authority has
25 sought or obtained access to medical information under this

1 section, and any written certification provided pursuant to
2 this section shall not be made, or considered, a part of the
3 medical information maintained by the facility about the
4 patient.

5 (c) Medical information disclosed by a medical care fa-
6 cility under this section shall not be further disclosed except,
7 if not otherwise prohibited by law, where necessary to fulfill
8 the purpose for which the information was obtained.

9 NEXT OF KIN

10 SEC. 129. A medical care facility may disclose medical
11 information it maintains about a patient, without the authori-
12 zation described in section 115(a), if the disclosure is to the
13 next of kin or legal representative of the patient or to individ-
14 uals with whom the patient has a personal relationship, is
15 consistent with accepted medical practice, and the patient
16 has not previously objected.

17 LAW ENFORCEMENT FUNCTIONS

18 SEC. 130. (a) A medical care facility may disclose medi-
19 cal information it maintains about a patient to a law enforce-
20 ment agency, without the authorization described in section
21 115(a), if—

22 (1) the information is (A) for use in an investiga-
23 tion or prosecution of fraud in a health or disability
24 program funded or operated by a government authori-
25 ty, (B) to assist in the identification or location of a

1 suspect, fugitive, or witness in a law enforcement
2 inquiry, (C) in connection with criminal activity com-
3 mitted at the medical care facility or against anyone
4 associated with the facility, or (D) needed to determine
5 whether a crime has been committed and the nature of
6 any crime that has been committed by a person other
7 than the patient; and

8 (2) where disclosure of medical information is re-
9 quested by the agency, the agency provides the facility
10 with a written certification that—

11 (A) is signed by a supervisory official of a
12 rank designated by the head of the authority,

13 (B) specifies the information requested, and

14 (C) states that the information is needed for
15 a lawful purpose under this section.

16 (b) Medical information disclosed by a medical care fa-
17 cility to an agency under this section shall—

18 (1) not be disclosed for, or used in, any adminis-
19 trative, civil, or criminal action or investigation against
20 the patient, except in an action or investigation arising
21 out of and directly related to the action or investigation
22 for which the information was obtained, and

23 (2) not be otherwise used or disclosed by the
24 agency, unless the use or disclosure is necessary to ful-

1 fill the purpose for which the information was obtained
2 and is not otherwise prohibited by law.

3 JUDICIAL AND ADMINISTRATIVE PROCEEDINGS

4 SEC. 131. (a) A medical care facility may disclose medi-
5 cal information it maintains about a patient, without the au-
6 thorization described in section 115(a) if the disclosure is
7 made pursuant to the Federal Rules of Civil or Criminal Pro-
8 cedure or comparable rules of other courts or administrative
9 agencies in connection with litigation or proceedings to which
10 the patient is a party.

11 (b) A person seeking medical information maintained by
12 a facility about a patient under this section shall provide the
13 facility with a written statement that the patient is a party to
14 the litigation or proceedings for which the information is
15 sought.

16 SUBPENAS, SUMMONS, WARRANTS, AND SEARCH

17 WARRANTS

18 SEC. 132. (a) A medical care facility may disclose medi-
19 cal information it maintains about a patient, without the au-
20 thorization described in section 115(a), if—

21 (1) the disclosure is pursuant to a subpoena issued
22 under the authority of a grand jury,

23 (2) the disclosure is pursuant to an administrative
24 summons, subpoena, or warrant, or a judicial summons,
25 subpoena, or search warrant and the conditions for such

1 disclosure under section 124 (relating to health re-
2 search), section 125 (relating to audits), section 126
3 (relating to health and safety), section 127 (relating to
4 legally required reporting), or section 130(a)(1)(A) (re-
5 lating to investigations or prosecutions of fraud) have
6 been met; or

7 (3)(A) the disclosure is pursuant to an administra-
8 tive summons, subpoena, or warrant or a judicial sum-
9 mons, subpoena, or search warrant, and (B) the facility
10 is provided a written certification by the person seek-
11 ing the information that the person has complied with
12 the applicable access provisions of section 141 or
13 143(a),

14 and the facility maintains a copy of the summons, subpoena,
15 warrant, or search warrant as part of the medical information
16 on the patient. Any person who obtains information under
17 paragraph (2) shall comply with the same conditions and re-
18 strictions on use and disclosure contained in the section for
19 which conditions for the disclosure are met.

20 (b) Medical information disclosed by a medical care fa-
21 cility under paragraph (2) or (3) of subsection (a) shall—

22 (1) not be disclosed for, or used in, any adminis-
23 trative, civil, or criminal action or investigation against
24 the patient, except in an action or investigation arising

1 out of and directly related to the inquiry for which the
2 information was obtained, and

3 (2) not be otherwise used or disclosed by the au-
4 thority unless the use or disclosure is necessary to ful-
5 fill the purpose for which the information was obtained
6 and is not otherwise prohibited by law.

7 (c) Nothing in this section shall be construed as
8 authority for a medical care facility to refuse to comply with
9 a valid administrative summons, subpoena, or warrant, or a
10 valid judicial summons, subpoena, or search warrant.

11 FEDERAL MEDICAL CARE FACILITIES

12 SEC. 133. (a) A medical care facility of a Federal Gov-
13 ernment authority, or other medical care facility providing
14 services on behalf of a Federal Government authority, may
15 disclose medical information it maintains about a patient,
16 without the authorization described in section 115(a), if the
17 disclosure is—

18 (1) to a component of the Veterans' Administra-
19 tion, and the information is needed to determine eligi-
20 bility for benefits under title 38, United States Code;

21 (2) to an official of the uniformed services (as de-
22 fined in section 2101(3) of title 5, United States Code)
23 and the information is needed to determine eligibility
24 for service-related benefits;

(3) by a medical care facility operated by the uniformed services (as used in paragraph (2)) to an official of the uniformed service for the purpose of determining eligibility of a member of the uniformed service for service, promotion, assignments, or training;

(4) to a congressional office or committee in response to an inquiry made by the patient, and the facility maintains an accounting (as defined in section 101(1)) of the disclosure; or

(5) for the purpose of filing a claim against a third party, if—

(A) the agency that operates facility is required by law to pay for medical services provided to the patient,

(B) there are reasonable grounds to believe that the third party is liable for the cost of the medical services provided to the patient, and

(C) the patient is notified in writing of the intended disclosure at least ten days before the date such disclosure is made.

(b) Medical information disclosed by a medical care facility under this section shall not be further used or disclosed except—

(1) where necessary to fulfill the purpose for which the information was obtained, or

1 (2) for a use permitted under the section 552a of
2 title 5, United States Code.

3 RESTRICTIONS ON USE OF MEDICAL INFORMATION BY
4 FEDERAL GRAND JURIES

5 SEC. 134. Medical information about a patient disclosed
6 by a medical care facility under section 132 (a)(1) pursuant to
7 a subpoena issued under the authority of a Federal grand
8 jury—

9 (1) shall be returnable on a date when the grand
10 jury is in session and actually presented to the grand
11 jury;

12 (2) shall be used only for the purpose of consider-
13 ing whether to issue an indictment or report by that
14 grand jury, or for the purpose of prosecuting a crime
15 for which that indictment or report is issued, or for a
16 purpose authorized by rule 6(e) of the Federal Rules of
17 Criminal Procedure;

18 (3) shall be destroyed or returned to the medical
19 care facility if not used for one of the purposes speci-
20 fied in paragraph (2); and

21 (4) shall not be maintained, or a description of the
22 contents of such information shall not be maintained,
23 by any government authority other than in the sealed
24 records of the grand jury, unless such information has
25 been used in the prosecution of a crime for which the

1 grand jury issued an indictment or presentment or for
2 a purpose authorized by rule 6(e) of the Federal Rules
3 of Criminal Procedure.

4 PART D—ACCESS PROCEDURES, CHALLENGE RIGHTS,
5 AND REPORTING

6 ACCESS PROCEDURES FOR LAW ENFORCEMENT SUMMONS-
7 ES, SUBPENAS, WARRANTS, AND SEARCH WARRANTS

8 SEC. 141. (a) No government authority may obtain
9 medical information about a patient from a medical care fa-
10 cility for use in a law enforcement inquiry pursuant to an
11 administrative summons, subpoena, or warrant or a judicial
12 summons or subpoena under section 132(a)(3) unless—

13 (1) there are reasonable grounds to believe that
14 the information will be relevant to the law enforcement
15 inquiry being conducted by the government authority;

16 (2) except as provided in subsection (c), a copy of
17 the summons or subpoena has been served upon the pa-
18 tient or mailed to his last known address on or before
19 the date on which the summons or subpoena was served
20 on the medical care facility, together with a notice
21 (published by the Secretary under section 153(a)(1)) of
22 the patient's right to challenge the summons or sub-
23 pena, in accordance with section 142; and

24 (3)(A)(i) ten days have passed from the date of
25 service or (ii) fourteen days have passed from the date

1 of mailing, and within such time period the patient has
2 not initiated a challenge in accordance with section
3 142, or

4 (B) disclosure is ordered by a court under such
5 section.

6 (b) A government authority which obtains a medical in-
7 formation about a patient from a medical care facility pursu-
8 ant to a search warrant shall, not later than forty-five days
9 after the date the search warrant was served on the facility,
10 serve the patient with, or mail to the last known address of
11 the patient, a copy of the search warrant.

12 (c)(1) A government authority may apply to an appropri-
13 ate court to delay (for an initial period of not longer than
14 ninety days) serving a copy of a summons or subpoena and a
15 notice otherwise required under subsection (a)(2) with respect
16 to a law enforcement inquiry. The government authority may
17 apply to the court for extensions of the delay.

18 (2) An application for a delay, or extension of a delay,
19 under this subsection shall state, with reasonable specificity,
20 the reasons why the delay or extension is being sought.

21 (3) If the court finds that—

22 (A) the inquiry being conducted is within the law-
23 ful jurisdiction of the government authority seeking the
24 medical information;

1 (B) there are reasonable grounds to believe that
2 the information being sought will be relevant to the
3 inquiry;

4 (C) the government authority's need for the infor-
5 mation outweighs the patient's privacy interest; and

6 (D) there is reasonable grounds to believe that re-
7 ceipt of a notice by the patient will result in—

8 (i) endangering the life or physical safety of
9 any person,

10 (ii) flight from prosecution,

11 (iii) destruction of or tampering with evi-
12 dence, or

13 (iv) intimidation of potential witnesses,

14 the court shall enter an ex parte order delaying, or extending
15 the delay of, the notice and an order prohibiting the medical
16 care facility from revealing the request for, or the disclosure
17 of, the information.

18 (3) Upon the expiration of a period of delay of notice
19 under this subsection, the government authority shall serve
20 upon the patient, with the service of the summons or subpoena
21 and the notice, a copy of any applications filed and approved
22 under this subsection.

1 CHALLENGE PROCEDURES FOR LAW ENFORCEMENT

2 SUMMONSES AND SUBPENAS

3 SEC. 142. (a) Within ten days of the date of service or
4 fourteen days of the date of mailing of a summons or subpena
5 of a government authority seeking medical information about
6 a patient from a medical care facility under section 132, the
7 patient may file (without filing fee)—

8 (1)(A) in the case of a State judicial subpena, in
9 the court which issued the subpena, or

10 (B) in the case of another subpena or summons is-
11 sued under the authority of a State, in a court of com-
12 petent jurisdiction; or

13 (2) in the case of a summons or subpena issued
14 under the authority of the United States, in the United
15 States district court for the district where the patient
16 resides or which issued the subpena,

17 a motion to quash the subpena or summons. A copy of the
18 motion shall be served by the patient upon the government
19 authority by delivery of registered or certified mail.

20 (b)(1) The government authority may file with the court
21 such affidavits and other sworn documents as sustain the va-
22 lidity of the summons or subpena. The patient may file with
23 the court, within five days of the date of the authority's filing,
24 affidavits and sworn documents in response to the authority's

1 filing. The court, upon the request of the patient, the govern-
2 ment authority, or both, may proceed in camera.

3 (c) The court may conduct such proceedings as it deems
4 appropriate to rule on the motion. All such proceedings shall
5 be completed, and the motion ruled on, within ten calendar
6 days of the date of the government authority's filing.

7 (d)(1) A court may deny a patient's timely motion under
8 subsection (a) if it finds that there are reasonable grounds to
9 believe that—

10 (A) the law enforcement inquiry is legitimate, and

11 (B) the information sought is relevant to that
12 inquiry,

13 unless the court finds that the patient's privacy interest
14 outweighs the government authority's need for the
15 information.

16 (2) In determining under this section whether a patient's
17 privacy interest outweighs the government authority's need
18 for the information, the court shall consider—

19 (A) the particular purpose for which the informa-
20 tion was collected by the facility;

21 (B) the degree to which disclosure of the informa-
22 tion will embarrass, injure, or invade the privacy of the
23 patient;

24 (C) the effect of the disclosure on the patient's fu-
25 ture medical examination, care, or treatment;

1 (D) the importance of the inquiry being conducted
2 by the government authority, and the importance of
3 the information to that inquiry; and

4 (E) any other factor deemed relevant by the
5 court.

6 The patient shall have the burden of demonstrating that his
7 privacy interest outweighs the need established by the gov-
8 ernment authority for the information.

9 (3) The court may assess against a Federal Government
10 authority attorney fees and other litigation costs reasonably
11 incurred in the case of any motion brought under subsection
12 (a) against the authority and in which the patient has sub-
13 stantially prevailed.

14 (e) A court ruling denying a motion to quash under this
15 section shall not be deemed a final order and no interlocutory
16 appeal may be taken therefrom by the patient. An appeal of
17 such a ruling may be taken by the patient within such period
18 of time as provided by law as part of any appeal from a final
19 order in any legal proceeding initiated against him arising out
20 of or based upon the medical information disclosed.

21 ACCESS AND CHALLENGE PROCEDURES FOR OTHER

22 SUMMONSES AND SUBPENAS

23 SEC. 143. (a) No person or government authority (other
24 than under section 141) may obtain medical information

1 about a patient from a medical care facility pursuant to a
2 summons or subpoena under section 132(a)(3) unless—

3 (1) there are reasonable grounds to believe that
4 the information will be relevant to a lawsuit or other
5 judicial or administrative proceeding;

6 (2) a copy of the summons or subpoena has been
7 served upon the patient or mailed to his last known ad-
8 dress on or before the date on which the summons or
9 subpoena was served on the medical care facility, to-
10 gether with a notice (published by the Secretary under
11 section 153(a)(2)) of the patient's right to challenge the
12 summons or subpoena, in accordance with subsection
13 (b); and

14 (3)(A) ten days have passed from the date of serv-
15 ice or fourteen days have passed from the date of the
16 mailing and within such time period the patient has not
17 initiated a challenge in accordance with subsection (b),
18 or

19 (B) disclosure is ordered by a court under such
20 subsection.

21 (b) Within ten days of the date of service or fourteen
22 days of the date of mailing of a summons or subpoena seeking
23 medical information about a patient from a medical care fa-
24 cility under subsection (a), the patient may file (without filing
25 fee) in the court or with the government authority that issued

1 the summons or subpoena, a motion to quash the summons or
2 subpoena, with a copy served on the person seeking the infor-
3 mation. The patient may oppose, or seek to limit, the sum-
4 mons or subpoena on any grounds that would otherwise be
5 available if the patient were in possession of the information.

6 CONSTRUCTION OF PART; SUSPENSION OF STATUTE OF
7 LIMITATIONS

8 SEC. 144. (a) Nothing in this part shall affect the rights
9 of a medical care facility to challenge requests for medical
10 information. Nothing in section 141, 142, or 143 shall entitle
11 a patient to assert the rights of a medical care facility.

12 (b) If a patient files a motion under this Act which has
13 the effect of delaying the access of a government authority to
14 medical information about the patient, any applicable statute
15 of limitations shall be deemed to be tolled for the period be-
16 ginning on the date such motion was filed and ending on the
17 date upon which the motion is decided.

18 REPORTS

19 SEC. 145. The Director of the Administrative Office of
20 the United States courts shall include in his annual report to
21 Congress (1) the number of delays of notice sought and the
22 number granted under section 141(c), (2) the number of suc-
23 cessful and unsuccessful challenges made under sections 142
24 and 143(b), and (3) such other information as he deems
25 appropriate.

PART E—ENFORCEMENT

CRIMINAL PENALTY FOR OBTAINING MEDICAL

INFORMATION THROUGH FALSE PRETENSES OR THEFT

SEC. 151. (a) Any person who, under false or fraudulent pretenses or with a false or fraudulent certification required under this Act, requests or obtains medical information about a patient from a medical care facility or an authorization from a patient to disclose such information shall be fined not more than \$10,000 or imprisoned for not more than six months, or both.

(b) Any person who, under false or fraudulent pretenses or with a false or fraudulent certification required under this Act, requests or obtains medical information about a patient from a medical care facility or an authorization from a patient to disclose such information and who intentionally sells or transfers such information for profit or monetary gain, shall be fined not more than \$30,000, or imprisoned for not more than five years, or both.

(c) Any person who unlawfully takes medical information from a medical care facility and who intentionally sells or transfers such information for profit or monetary gain shall be fined not more than \$30,000, or imprisoned for not more than five years, or both.

CIVIL SUITS

1
2 SEC. 152. (a) Any patient whose rights under this title
3 have been knowingly or negligently violated—

4 (1) by an officer or employee of—

5 (A) the United States,

6 (B) any authority of a State which has
7 waived its sovereign immunity under the Consti-
8 tution to a claim for damages resulting from a
9 violation of this title, or

10 (C) any other government authority,
11 while the officer or employee was acting within the
12 scope of the office or employment, may maintain a civil
13 action for actual damages and for equitable relief
14 against the United States, the State authority, or the
15 other government authority, respectively;

16 (2) by an officer or employee of—

17 (A) a government authority of a State not
18 described in paragraph (1)(B), or

19 (B) another government authority, while the
20 officer or employee was not acting within the
21 scope of the office or employment,
22 may maintain a civil action for actual damages and for
23 equitable relief against the employee or officer; or

24 (3) by a medical care facility, health researcher,
25 auditor, or any other person, may maintain a civil ac-

1 tion for actual damages and for equitable relief against
2 the researcher, auditor, or other person.

3 The district courts of the United States shall have jurisdiction
4 in actions brought under this section.

5 (b)(1) Any patient entitled to recover actual damages
6 under this section because of a knowing violation of this title
7 shall be entitled to recover the amount of the actual damages
8 demonstrated, or \$1,000, whichever is greater.

9 (2) In any suits brought under this section in which the
10 complainant has substantially prevailed because of a knowing
11 violation of this title, the court may, in addition to any actual
12 damages or equitable relief, award such punitive damages as
13 may be warranted and may assess against the defendant rea-
14 sonable attorney fees and other costs of litigation reasonably
15 incurred.

16 (c) If a medical care facility has established a written
17 internal procedure that allows a patient who has been denied
18 inspection or amendment of medical information to appeal the
19 denial, the patient may not file a civil action in connection
20 with the denial until the earlier of (1) the date the appeal
21 procedure has been exhausted or (2) five months after the
22 date the original request for inspection or amendment was
23 made.

24 (d)(1) A medical care facility that makes a disclosure of
25 medical information about a patient that is permitted by this

1 title and not otherwise prohibited by law shall not be liable to
2 the patient for such disclosure.

3 (2) If the members of an institutional review board have
4 in good faith determined that a health research project is of
5 sufficient importance to outweigh the privacy interest of a
6 patient, the members, the board, and the parent institution of
7 the board shall not be liable to the patient as a result of that
8 determination.

9 (3) A medical care facility that relies in good faith on a
10 certification by a government authority or other person and
11 discloses medical information about a patient in accordance
12 with this title shall not be liable to the patient for such
13 disclosure.

14 (4) A medical care facility that determines in accordance
15 with section 103(2) and in good faith that a patient suffers
16 from a medical condition that prevents the patient from act-
17 ing knowingly or effectively on the patient's own behalf shall
18 not be liable to the patient as a result of that determination.

19 RESPONSIBILITIES OF SECRETARY

20 SEC. 153. (a) The Secretary shall promulgate, by regu-
21 lation, a notice—

22 (1) for use under section 141(a)(2), detailing the
23 rights of a patient who wishes to challenge, under sec-
24 tion 142, the disclosure of medical information about
25 the patient under such section, and

1 TITLE III—TRANSITION AND EFFECTIVE DATES

2 CONTINUED APPLICABILITY OF ACT

3 SEC. 301. If a facility ceases to be a medical care
4 facility, the provisions of this Act shall continue to apply to
5 medical information maintained by the facility and obtained
6 by the facility before it ceased to be a medical care facility.

7 EFFECTIVE DATES

8 SEC. 302. (a)(1) Except as otherwise provided in this
9 subsection, this Act and the amendments made by this Act
10 shall take effect on the first day of the first calendar quarter
11 beginning more than one year after the date of the enactment
12 of this Act.

13 (2) This Act and the amendments made by this Act shall
14 apply with respect to Federal medical care facilities on the
15 first day of the first calendar quarter beginning more than
16 one hundred and eighty days after the date of the enactment
17 of this Act.

18 (3) Section 151 shall take effect on the date of the en-
19 actment of this Act.

20 (4) Unless otherwise prohibited by law, an authorization
21 of disclosure of medical information which—

22 (A) was granted by a patient before the applicable
23 effective date of this Act,

1 (B) which was legally sufficient to authorize dis-
2 closure of medical information on the date before such
3 effective date, and

4 (C) is not legally sufficient under section 115,
5 shall nevertheless be valid for two years from such effective
6 date unless the authorization is revoked by the patient as
7 provided in section 115(b) or otherwise expires.

8 (b) The Secretary shall first establish final regulations to
9 carry out section 153(a) not later than the first day of the
10 second month that begins before the effective date specified
11 in subsection (a)(2).

12 (c) If any provision of this Act, or the application of
13 such provision to any person or circumstance, shall be held
14 invalid, the remainder of this Act, or the application of such
15 provisions to persons or circumstances other than those as to
16 which it is held invalid, shall not be affected thereby.

Mr. WEISS. If you would identify yourself for the record, Mr. Geller, as well as your associate with you, we can proceed.

STATEMENT OF HENRY GELLER, ASSISTANT SECRETARY, COMMUNICATIONS AND INFORMATION, U.S. DEPARTMENT OF COMMERCE; ACCOMPANIED BY ARTHUR BUSHKIN, DIRECTOR, INFORMATION POLICY PROGRAM, NATIONAL TELECOMMUNICATIONS AND INFORMATION ADMINISTRATION

Mr. GELLER. My name is Henry Geller. I am the Assistant Secretary of Commerce for Communications and Information. I am accompanied here by Mr. Arthur Bushkin to my right. He is the Director of the information policy program at NTIA, the National Telecommunications and Information Administration.

Mr. WEISS. The statement which you have prepared will be entered into the record, without objection, and you may proceed as you see most appropriate.

[Mr. Geller's prepared statement follows:]

Testimony
of
Henry Geller,
Assistant Secretary, Communications and Information
U.S. Department of Commerce
before
Subcommittee on Government Information & Individual Rights
Committee on Government Operations
U.S. House of Representatives
April 4, 1979

I am Henry Geller, Assistant Secretary of Commerce for Communications and Information.

I would like to thank you for the opportunity to appear before you today to describe the Administration proposals for a national policy on personal privacy. These proposals were officially transmitted to the Congress on April 2, 1979 in a Message from President Carter. In the message, the President outlined the two key principles of the national policy being proposed by the Administration:

- o First, sensitive, personal records must be provided privacy protections according to a set of "Fair Information Practices," modeled on those outlined by the Privacy Protection Study Commission.
- o Second, government access to, and use of, personal information must be limited and supervised so that power over information cannot be used to threaten our liberties.

As you know, in 1977 the Privacy Protection Study Commission--created by the fine work of your committee

in the Privacy Act of 1974--presented its Report and recommendations to this Committee, the Congress, the President and the public. Upon receiving the Report, President Carter directed that an Interagency Task Force evaluate the Commission's proposals and make further recommendations. The Task Force examined the specific recommendations of the Commission. We then drafted legislation translating the policy proposals into statutory language. As part of the drafting process, we consulted with private industry and other interested groups.

C. L. Haslam, General Counsel of the Department of Commerce, testified before this Committee in June of 1978 regarding the progress of the Task Force. In December, the Task Force made its recommendations to the President. We found that the detailed legislative recommendations of the Privacy Commission and the policy recommendations of the Interagency Task Force were still a long step away from workable statutory proposals. While the legislative proposals do not follow the Commission in all of their specific detail, it should be clear that the Administration accepts and endorses the approach to personal privacy which the Commission and so many others have proposed. As you

know, translating the recommendations of a study commission into statutory language is a difficult task which often requires recasting the language of a recommendation in order to achieve its goals. The Administration has tailored the legislation to minimize the costs of implementation in the private sector, while still providing strong privacy protections to individuals.

Today, I will discuss with you the package of privacy legislation, administrative actions and voluntary guidelines which comprise the Administration's program. With the President's Message were three legislative proposals: the "Privacy of Medical Information Act," the "Privacy of Research Records Act," and the "First Amendment Privacy Protection Act of 1979". A fourth, multi-part bill, the "Fair Financial Information Practices Act" will be transmitted to the Congress later in the spring. This last bill establishes protection for the privacy of records held by consumer reporting agencies, credit grantors, check authorization and guarantee services, depository institutions, insurance companies, and Electronic Funds Transfer (EFT) service providers.

I will briefly outline the proposed national policy objectives and the proposed individual rights in the legislative package. I will be glad to answer questions you

may have regarding this proposed legislation, however I will defer to the representative of the Department of Health, Education and Welfare to answer questions concerning the Medical Records bill.

The proposed national policy is designed to protect personal privacy in today's electronic information society. Its objectives are to:

- o Halt the erosion of personal privacy which results from incremental, and generally well-intentioned, changes in the way private organizations and government collect, use and disseminate personal information.
- o Balance privacy protection with competing interests. The legislation recognizes the importance of safeguarding individual privacy while protecting legitimate information needs of business, government, and other institutions.
- o Avoid creating new regulatory structures or imposing heavy costs, and emphasize voluntary efforts where government regulation is not needed. Where voluntary compliance could sufficiently protect individual rights, legislation has not been recommended. The government will encourage and help develop guidelines for voluntary efforts.

Basic Privacy Rights

The Administration's policy recognizes certain basic principles concerning the privacy rights of individuals in recorded information which an organization collects and maintains about them. An individual should have:

- o A right to know the information collection and disclosure practices of an organization, and the organization should be obliged to adhere to the practices it has established;
- o A right to see and obtain a copy of records about himself;
- o A right to challenge the accuracy of information about himself, with assurance that the record will be either corrected or amended to report his dispute;
- o A right to know the reasons for an adverse decision made about him, and to be able to see the information used in making that decision; and
- o A legally enforceable expectation of confidentiality for certain records, so that sensitive personal information about him will not be disclosed by an organization without authorization or without the individual, in most instances, being able to challenge that disclosure in court.

We should not lose sight of these important principles in working out the specific details of this legislation. They provide to each citizen a set of fundamental rights with regard to recorded information about him--rights which will be of ever increasing importance as society continues to grow and evolve. I will now turn to the specifics of each bill.

The "Privacy of Medical Information Act"

The "Privacy of Medical Information Act" establishes important privacy protections for individuals with regard to medical information maintained by medical institutions. This bill is designed to protect an individual's right to privacy and accuracy in medical records, while avoiding interference in the sensitive doctor/patient relationship. Specifically, the bill:

- o Establishes privacy protections for information maintained by hospitals and other in-patient medical facilities, and any out-patient clinic or facility receiving Federal assistance;
- o Allows individuals to participate in decisions to disclose their medical records when the records will be used to affect them, with some limited exceptions for emergency uses;
- o Gives individuals the right to see their own

medical records. Where direct access to those records might harm the patient, access can be provided through an intermediary selected by the patient;

- o Allows the individual to ensure that records maintained as part of a medical-care relationship are accurate; and
- o Makes it a crime to obtain medical record information under false pretenses.

It is, perhaps, most important that this bill clearly limits the disclosure of this sensitive personal information. It establishes an expectation of confidentiality for individuals with regard to their medical records, and sets strict penalties for any improper disclosure. Yet, at the same time, the legislation allows the flexibility of disclosure which is vital for proper medical care, and for the valuable research and statistical, particularly epidemiological studies, which utilize information from medical records.

"Privacy of Research Records Act"

The "Privacy of Research Records Act" concerns the use of personal information for research studies--a use which requires a careful balancing of the individual's interest in privacy with society's need for knowledge.

Unlike other uses of personal records, research studies do not directly benefit the individual to whom the records pertain. Yet, at the same time, information contained in these records can be intensely personal and, if disclosed, may cause great harm to the individual. Medical, social service, and other researchers depend upon access to these records to conduct studies which benefit our entire society, and they often promise confidentiality to those who participate or allow their records to be used. Today, however, virtually no legal basis for this promise of confidentiality exists.

The "Privacy of Research Records Act" establishes clear protection for the individual whose records are used in research, but it will also allow for the continuation of valuable studies. The legislation establishes a policy of "functional separation" so that no personal information collected or maintained for a research purpose may be used or disclosed in individually identifiable form to allow the making of any decision which may adversely affect the individual to whom the record pertains.

Specifically, the bill:

- o Provides for a legal standard of confidentiality which would allow researchers to release information for non-research purposes only to prevent

physical injury to an individual or in a medical emergency;

- o Ensures that research subjects are not recontacted by other researchers in a way that would embarrass or inconvenience them or otherwise intrude on their privacy.
- o Requires the researcher to tell research subjects of the possibility, if any, that information about them will be disclosed.
- o Provides criminal fines for unauthorized disclosure of research information, and gives individuals the right to sue for damages caused by any violation of the Act.

First Amendment Privacy Protection Act of 1979

The United States Supreme Court's decision in Zurcher v. Stanford Daily--which permitted police to use a search warrant to seize a reporter's notes--has raised serious concerns among many, including the Administration, over the effective functioning of a free press. The Administration is committed to developing measures to protect First Amendment activities from unnecessarily intrusive searches, and still preserve legitimate law enforcement interests. Although requests for the issuance of subpoenas to the news media by Federal officers presently are limited strictly

by regulation, the Administration believes that the problems raised by Stanford Daily demand legislation to impose more stringent safeguards against Federal, state, and local governmental intrusion into a wide range of First Amendment activities. The President's announced legislation is designed to severely restrict third party searches for documentary materials held by the press and others involved in the dissemination of information to the public.

The premise underlying this legislation is that, absent extraordinary circumstances, such as the endangerment of life, the appropriate means of obtaining documentary evidence which is produced or possessed by persons involved in First Amendment activities (who are themselves not implicated in the commission of the crime under investigation) is through the use of a subpoena duces tecum rather than a warrant permitting a search for and seizure of materials in the homes and offices of reporters and others engaged in the preparation of information for the public.

Fair Financial Information Practices Act.

The proposed Fair Financial Information Practices Act which will be submitted to the Congress later this spring builds on existing consumer protection legislation like the Fair Credit Reporting Act, Equal Credit Opportunity Act, the Fair Credit Billing Act, and Truth in Lending.

It establishes privacy protection for records maintained by:

1. Consumer reporting agencies;
2. Credit grantors;
3. Credit and check authorization and guarantee services;
4. Depository institutions;
5. Insurance companies, agents, and insurance-support organizations; and
6. Electronic Fund Transfer (EFT) systems.

I will outline the provisions of this multi-part bill as they apply to these different types of record keepers.

Consumer Reporting Agencies

The Fair Credit Reporting Act (FCRA) was passed in 1970 to regulate the information collection and reporting practices of credit bureaus and consumer reporting agencies. The Act established in Federal law minimum privacy protections for individuals who were the subject of consumer reports: consumers of insurance and credit services, and applicants for employment.

The protections established in the FCRA for the records of consumer reporting agencies and credit bureaus must be strengthened. The Fair Financial Information Practices Act proposes amendments to the Fair Credit Reporting Act

which would:

- o , Give consumers the right to see and copy investigative consumer reports about them. Previously, consumers had only the right to learn the nature and substance of those records;
- o Improve the consumer's ability to correct disputed consumer reports; and
- o Prohibit "pretext" interviews (i.e., interviews conducted under false pretenses) to collect information for investigative consumer or credit reports.

Credit Grantors

Credit records frequently present a detailed history of an individual's life. The slips from credit transactions can show where an individual shops and travels, the kind of clothing he buys, the food he eats, where he works, and many other indices of his style of living. The information collected and reported by credit bureaus and other service organizations to the credit industry is already regulated by the Fair Credit Reporting Act, as well as some portions of statutes such as the Equal Credit Opportunity Act and Fair Debt Collection Practices Act which protect the consumer of credit services from certain abusive information practices. Yet these laws fail to provide consistent

and clear privacy protections regarding the information collected, maintained and reported by credit grantors themselves. The Fair Financial Information Practices Act will give individuals privacy protections for most of the records used in evaluating whether he receives credit and in servicing existing credit accounts. Specifically, the legislation will:

- o Require credit grantors to inform individuals about their information collection and disclosure practices;
- o Provide that individuals be informed by a credit grantor of both the reasons for any adverse decision made about them and the items of information used to support the decision; and
- o Create a clear, legally-enforceable "expectation of confidentiality" regarding disclosure of records. An important feature is that the individual will have the legal right to challenge a request for disclosure of the records.

Credit and Check Guarantee and Authorization Services

In order to better serve consumers and to prevent fraud and abuse, our modern credit and banking systems have spawned the development of new types of service organizations: credit-card and check authorization and guarantee

services. These organizations provide information to merchants at the point of sale or payment so that they can determine whether to accept a credit card or check. These services also sometimes guarantee particular transactions. These organizations rely heavily on personal information reported to them from banks, creditors, employers and other sources. The information they report about individuals, if inaccurate or misleading, may cause great inconvenience or problems to a consumer. It is thus important that privacy protections be established regarding the records used by these services so that individuals--and the organizations themselves--may better assure the accuracy of the information flowing within the system.

The provisions of the bill covering these services will:

- o Ensure that independent authorization services maintain reasonable procedures to assure the accuracy of the information they collect and report;
- o Establish procedures to speed the correction of inaccurate information maintained by authorization services; and
- o Create a clear, legally enforceable expectation of confidentiality.

Depository Institutions

The information accumulated by banks, savings and loan associations, and credit unions in the process of providing checking and depository services can become a virtual economic and social diary of an individual. In order to assure the confidentiality of these records, this bill regulates the disclosure of individual checking and savings account records.

Specifically, the proposed legislation will:

- o Require depository institutions to notify individuals of their record-keeping practices, and to follow that notice; and
- o Create a clear, legally enforceable expectation of confidentiality.

Insurance Information Practices

Insurance companies collect a great deal of highly personal information about individuals in the course of their business, both in the underwriting of insurance coverage and the settlement of claims. This part of the legislation will establish privacy protections for the records collected and maintained by insurance companies, their agents, and insurance-support organizations.

Specifically, the legislation will:

- o Provide that individuals be notified of the in-

formation collection and disclosure practices of insurers;

- o Grant individuals the right to see, copy, correct, and amend insurance records about them;
- o Require individuals be informed by an insurer of the reasons for adverse decisions about them, and provided with the items of information used to support that decision; and
- o Establish a clear legally enforceable expectation of confidentiality for individuals in their insurance records.

This legislation will be enforceable by the individual through a right of action in Federal District Court, and by State Insurance Commissioners through their existing administrative and judicial procedures, as well as a right of action in Federal District Court. This legislation will not create new Federal regulatory authority for insurance, and it does not compromise the existing authority of the States to regulate insurance practices.

Electronic Funds Transfer (EFT) Systems

The Administration believes that protection must be afforded EFT transaction data as it flows through an EFT data communications network. This bill will erect safeguards against misuse of EFT systems for surveillance purposes,

while allowing adequate flexibility for commercial and technological innovation.

Non-Legislative Actions

This concludes the description of the legislative portion of the Administration's proposals. Let me now describe the other elements of the package.

Employment and Personnel Records

Based upon all of the studies which have been done to date, including that of the Privacy Commission, it appears that Federal laws in the employment area would be difficult to enforce without creating an elaborate regulatory structure. We are still studying this question. In the meantime, the Privacy Commission Report contained extensive recommendations for actions which private employers can implement on a voluntary basis to protect the privacy of their employees. The President endorses these recommendations as guidelines for private sector employers, and has instructed the Department of Labor and other appropriate agencies to monitor voluntary compliance by employers. These agencies will also consider the future need for an amended voluntary code, or perhaps Federal legislation.

Federal legislation is, however, needed at this time in one limited aspect of employee privacy. The use of polygraph and other truth verification devices in private

sector employment should be severely restricted. Such legislation has already been introduced in this Congress. The Administration will support legislation in this area.

Commercial Credit

The concern in the area of commercial credit is that personal information may figure extensively in the credit granting decisions for smaller businesses, such as partnerships and sole proprietorships. Individuals who run small businesses should be able to see and copy, and challenge the accuracy of, commercial credit reports containing personal information about them. They should also know if this personal information was the basis of an adverse commercial credit decision. Nonetheless, while these are important rights, it is not clear that privacy protections such as these are an appropriate matter for Federal legislation. Thus, the Administration has urged that commercial credit grantors and commercial reporting services voluntarily implement privacy measures relating to the personal information used in business credit decisions. The Federal agencies--and perhaps the Congress as well--will continue to study this question, and will monitor voluntary progress in this area.

Public Assistance and Social Services

Our public assistance and social service system depends

heavily upon the collection and use of personal information. Those seeking assistance generally must disclose sensitive personal information about themselves in applying for aid, and this information is subject to extensive verification. There is, in most cases, a clear and valid need for this information, whether for making a decision related to the individual, or for auditing and ensuring the integrity of the system. Yet, this does not mean that a recipient or applicant for public assistance should be without personal rights, such as privacy. Indeed, it is particularly important that privacy protections be incorporated into the information systems of public assistance and social service agencies, since the individual is often not in a position to assert those rights for himself.

In his Message, the President called upon the States to adopt legislation to protect the rights to privacy of recipients of public assistance and other social services. The Department of Health, Education, and Welfare is also developing minimum protection standards for Federally funded programs, while maintaining adequate access to data for verification and other purposes.

Wiretapping

Title III of the Omnibus Crime Control and Safe Streets Act of 1968 governs the use of electronic surveillance

of wire and oral communications except in matters involving foreign intelligence or counterintelligence. The National Commission for the Review of Federal and State Laws Relating to Wiretapping and Electronic Surveillance studied the situation under Title III and issued findings and recommendations. The President has sent to Congress a letter which:

- o Endorses in general the recommended adjustments to strengthen Title III's protections for individual privacy; and
- o Does not support the recommendation to amend the law to allow Federal officials below the rank of Assistant Attorney General to apply to the courts for wiretaps. The President believes that such a change would diminish accountability and increase the danger of misuse.

Administrative Actions for Federal Records

In addition to these proposals slated for legislative and voluntary action, the President has announced a number of administrative actions to further individual privacy in Federal record-keeping. First, the Office of Management and Budget has issued new guidelines for the Federal agencies in their use of computerized "matching programs". The use of these programs by the Federal government raised significant public concern when two such projects were

announced last year. The new guidelines will ensure that these programs are conducted:

- o only after the public has been notified and given the opportunity to identify privacy problems;
- o with tight safeguards on access to the data and to the names of suspects identified by the matching process; and
- o only when there are no viable, alternative means of identifying violators.

These guidelines are not designed to facilitate the widespread use of matching programs, but rather to control their use and protect the privacy of individuals when they are employed. Just as we cannot allow fraud and abuse in Federal government programs, so can we not permit our efforts in pursuing fraud and abuse in these programs to deprive those who derive the benefits and services of those programs of their basic human rights.

The President has also directed that action to be taken to:

- o Extend the applicable requirements of the Privacy Act to data systems operated by certain recipients of discretionary Federal grants;
- o Strengthen administration of the "routine use" provision of the Privacy Act, which governs dis-

- closures of personal information by Federal agencies;
- o Ensure that each Federal agency has an office responsible for privacy issues raised by the agency's activities;
 - o Improve the selection and training of the system managers required by the Privacy Act;
 - o Establish mechanisms to improve oversight of new Federal information systems at an early stage in the planning process; and
 - o Strengthen oversight of the reports Federal agencies require individuals and organizations to fill out, helping to protect privacy by reducing the amount of information the government collects in the first place.

Follow-on Responsibilities

The responsibilities for implementing the administrative actions for Federal records outlined above will rest with the Office of Management and Budget.. The Department of Commerce through my own organization, the National Telecommunications and Information Administration, has been assigned the lead role in other privacy matters, including working with the Congress in the continuing development of privacy policy.

Conclusion

Privacy is a vital human right in our society, essential to the individuality and anatomy of each American citizen. As records become more plentiful and more important, and as information technologies continue to develop, the need for the individual to participate in the control of the collection, use and disclosure of information about him will grow.

I call on the Congress to act favorably on the new legislative privacy proposals which I have described today and to assist in encouraging the development of voluntary action in this important area.

Thank you.

Mr. GELLER. If I may, I will just go over some highlights of my statement and then be glad to answer your questions.

The purpose of the President's program that you referred to is to halt the erosion in individual privacy that has occurred. It used to be that individuals had control over sensitive personal information. Today, as you make clear, that is fast eroding. An individual has to get credit, has to go into a hospital, has to get insurance. When he does so, he gives up a great deal of information about himself.

That goes into computers and is flashed around the country. He has lost control over it.

The purpose of the President's program is to redress the balance, to give the individual rights in that process.

We are building on a very solid base. For that base we are very grateful to this subcommittee. In 1974, the subcommittee enacted the Privacy Act that is applicable to the Federal Government. That act also called for a study by an independent Commission as to whether the principles embodied in it should be made applicable to the State and local governments and to the private sector.

That Commission was established under the able leadership of David Linowes. It got out its report in 2 years. It was a very comprehensive report, it answered the question yes, the principles should be made applicable to the private sector.

It, also, however, made clear that it could not be done simply across the board. Each industry had to be treated in light of its own problems.

The President received that report in 1977. He pledged that it would not gather dust, that he would show strong leadership in enacting its recommendations. He therefore instituted an inter-agency committee under Stuart Eizenstat and the Department of Commerce. That committee has worked on these complex issues for the past year.

What has evolved is the overall policy that is now before you.

There are two basic principles in that policy. One of them is fair information practices. The other is limitations on Government access to personal data.

In the first area, the principles have been to a great extent derived from the work of this subcommittee in 1974. An individual should know what information is being collected about him, how it is being collected, to whom it is going to be disclosed. He should have a right to see and copy his file. He should have a right to correct it. He should have a right to know about adverse decisions and the personal data upon which they are based. And there should be a legal right of expectation of confidentiality as to the sensitive material. They should not be improperly disclosed.

In applying these principles in this policy initiative, there are several important considerations.

The first is that our policy does not interfere with the flow of needed information to business or to the Government.

The second is that we have not put any undue burden upon industry. We have taken into account the recommendations of the Privacy Commission in this respect. We have touched base with industry groups and with public groups to try to strike a proper balance here, and we believe we have.

We have tried to craft the policy so that it does not place an undue imposition or burden upon the particular record gatherer.

Moreover, we have called upon voluntary action where that is appropriate.

The third consideration is that we have imposed no new Federal regulatory structure. We relied upon existing structure. In general, we have followed the principle that the individual should be given his rights and then allowed to protect them himself in the courts.

On the second broad principle I mentioned, limitation on Government, we believe that Government access to personal information must be limited and supervised so that the enormous power the Government may have over information cannot be used to threaten our liberties.

As this subcommittee is aware, in the 1976 decision *United States v. Miller*, the Supreme Court held that records a bank has concerning you do not belong to you; they belong to the bank, and you have no constitutional right to prevent their dissemination. The Court said that any change here was up to Congress.

With the strong backing of the administration, Congress did act last year and passed the Right to Financial Privacy Act. That changes the situation and strikes an entirely different balance. The individual has legal rights, in this situation. He must be notified when the Government seeks access to his records. And he has a right to challenge in court. That is, as we say, a fundamental difference.

To implement these two principles, the administration has four pieces of legislation.

The first is the Privacy of Medical Information Act. That is what is before you today. Mr. Libassi will be speaking upon it, so I will not go over that.

The second is the Privacy of Research Records. Here we have sought to introduce the principles I refer to in the research field when Federal funds are involved. Individuals who are the subjects of research do not get any direct benefit out of that research. Yet it is extremely important to the Nation that it go forward. Therefore, researchers promise confidentiality today in order to induce people to give up what is often very sensitive personal data.

There is no legal basis for their promise however. This bill would change that. There would be what we call a functioning separation of records used for research from any other use of those records. No information that was put into the research product could be used against the individual.

There would be a complete separation with two very narrow exceptions. One would be if a crime of violence were involved. The other would be in a medical emergency involving the individual.

In all instances other than these, privacy would be guaranteed. We believe this will facilitate research. It will give the people the assurance they need to engage in the project.

A third bill is the First Amendment Privacy Protection Act. This bill deals with the Stanford Daily situation. You recall in *Stanford Daily* that the police obtained a search warrant. They went to the offices of the Stanford Daily in order to go through the files to look for photos. The Stanford Daily itself was not accused of any wrongdoing and was not involved in any wrongdoing.

The *Stanford Daily* argued that this search violated their constitutional rights as guaranteed by the first and fourth amendments. The Supreme Court disagreed.

Again, the case went off on constitutional ground. The Court said that any remedial action would be a matter for Congress.

The President believes that the *Stanford Daily* decision poses a severe threat to journalism and that it can have a chilling effect on the dissemination of information to the public. The bill that we have drafted would change this.

The bill would proscribe the Government from using searches in order to obtain work product which was created by those engaged in the dissemination of information to the public. So, this would be a very broad and important right.

There would be two narrow exemptions, and where work product is not involved, the Government, nevertheless, would have to proceed with a subpoena-first rule generally.

The fourth bill in this privacy initiative is the Fair Financial Information Practices Act. That bill is being drafted. We are still going out contacting public groups and industry groups.

This bill would deal with consumer reporting agencies, credit grantors, credit and check authorizations, guarantee services, depository institutions, insurance companies, and the electronic fund transfer systems.

In the area of consumer credit, it would tighten the present law, the Fair Credit Reporting Act. It would improve procedures.

In the area of insurance, it would, for the first time, lay down Federal protection for the records insurance companies keep about individuals. However, the implementation of this Federal privacy protection would not be provided by the Federal Government. The protection would stem, rather, from an individual's being able to sue in court or from a State commission's being able to implement the provisions of the bill.

In the EFT area, we are dealing with a new phenomenon. More and more checks are being deposited electronically. Mortgage payments are made electronically. People make purchases at a point of sale in a department store, and these can be electronically registered.

All this is to the good, but it means that in this electronic funds transfer, enormous amounts of information are built up. You could compile a virtual dossier on a person, knowing all his habits.

EFT systems pose a second potential threat to privacy. That is that with them you can place surveillance on an individual. These systems are on-line, computer networks. If the computers are programmed correctly, you can determine that an individual in a store in Peoria has bought a particular item at a particular moment.

Clearly there is a need for privacy protection and for court supervision of this process. That is what the bill now being drafted will do.

That is the program. The President has also called upon the States to take action, to adopt privacy policies in this field; that is, in their recordkeeping and particularly their criminal justice systems.

He has called upon the States to adopt privacy protections in those areas of public assistance that they fund. He has called upon

HEW to develop minimum privacy standards for federally funded programs.

As I have said, the President's policy calls for voluntary action, with respect to commercial credit and employment. In the area of employment, there are now a number of voluntary programs, sponsored by such organizations as the NAM, the Business Roundtable, the Chamber of Commerce.

The Secretary of Labor will be doing all he can to bring about adoption of those programs.

The President has also said that he supports the principle of restricting the use of lie detectors, the polygraph, in employment situations, as proposed in the bill introduced by Senator Bayh.

The administration will also be taking action within its own house. We have, for example, adopted new safeguards for privacy in our computer matching programs, a subject that this subcommittee has been so involved in and has been so helpful to us.

We have also specified that each agency or department must have an officer in charge of privacy. We are improving the training of the officers who are in charge of these systems.

We are extending privacy protection to certain Federal grantees.

So, then, to repeat, we are taking a number of actions along these lines to enhance privacy within the administration's own bailiwick.

This has been a very skeletal review, Mr. Chairman, of the program. We regard this privacy program as of the highest importance. We believe that privacy, is a vital right in our society and that it is essential to the individuality of each American citizen.

We look forward to working very closely with this subcommittee on this most important endeavor.

That concludes my highlights. I would now be glad to try to answer your questions on the general administration program.

Mr. PREYER [presiding]. Thank you very much, Mr. Geller.

I know the committee commends you and the administration for your interest in this important field, a relatively new field. We look forward to working with you on it.

I think you have given us a very good overview, as you said, of the basic principles, the need, and the priority which you attach to this whole effort.

On the subject of priorities, the President's privacy package contains recommendations for a number of different bills. You have outlined them here.

What are your priorities on these bills? Which ones do you think we ought to consider first?

Mr. GELLER. We would hope that this subcommittee would assign the medical records bill the high priority and, second, the research bill. We also will be proposing the fair financial information practices bill, which will go to the Banking Committee. We would hope that it would proceed with that.

There is, we believe, a clear and compelling need for action with regard to the *Stanford Daily* case. That bill will go to a different committee, the Judiciary.

We are hopeful that there will be action concurrently in all these areas.

Mr. PREYER. So, we will attack on a lot of fronts at once?

Mr. GELLER. That is right.

Mr. PREYER. The President's message to Congress indicated that the Privacy Act of 1974 was too new for revision at this time. The Privacy Commission, as you know, recommended an overhaul of that law 2 years ago. At what point do you think it would be appropriate to consider amending the Privacy Act?

Mr. GELLER. We believe, first, that we should take the steps we have outlined ourselves to improve the Privacy Act. That bill was passed in 1974, and was made applicable only in late 1975.

We are now engaged in improving it through administrative means. For example, we are looking at the routine use problem. This year we will endeavor to take steps to correct problems that have arisen in that area.

We believe that we ought to wait a couple of years to see whether these administrative actions have been effective. So, I think what we are talking about would be more in the line of two years from now.

Mr. PREYER. We would be interested in the results of your study of that act as to which aspects of it you think are working reasonably well and which are not. I hope your administrative remedies might solve all the problems involved.

The Privacy Commission also recommended changes in Federal laws protecting the confidentiality of educational and tax records. Maybe we should not complain that you have not included any more than you have. Is there any particular reason why these were not included? Or are you planning to go into that area?

Mr. GELLER. Well, that gets back to your first question, Mr. Chairman, and the matter of priorities. The Privacy Commission did make recommendations in each of these areas, and we did look at them. But in each of these areas they felt that the law which had recently been enacted—1976 in the case of the Tax Reform Act—had very substantially improved the situation.

It seemed to us a matter of priorities. After looking at the fields that we are considering today before you—medical, insurance, and others—it was decided that, as a matter of priority, what was needed in the education and tax areas was more fine-tuning. Therefore, we have decided to put those two areas on a back burner and, in terms of legislation, to go forward with what is more urgently needed. We shall await further experience with these other two areas that have been the subjects of recent attention and are working, we think, fairly well.

Mr. PREYER. Would that be true also of the privacy of telephone toll records?

Mr. GELLER. In that area there is a difference. There is no legislation, unlike the case of tax reform. There is, however, a Supreme Court case pending; I believe it was just argued last week. We are awaiting a decision on that case because of its pertinence. If the Court, for example, holds that under the fourth amendment a search warrant is required whenever one wishes to obtain telephone toll records, then that would of course be a very important statement of rights and would affect whatever is done here.

So, we are awaiting the Court's handling of the issue before we ourselves turn to it as a matter of policy.

Mr. PREYER. Thank you.

Mr. Kindness?

Mr. KINDNESS. Thank you, Mr. Chairman.

Mr. Geller, there are two areas principally in which I would like to solicit your comments and advice. One is with respect to medical records.

The hospital field has experienced quite a bit of daily living with Federal regulations, let us say, in recent years. Do you anticipate that the concept of this legislation would impose any new requirements in terms of personnel and added cost? Assuming that the answer is yes, I am talking about substantial additional costs in the health care field attributable to legislation such as this—do you have any input on that yet?

Mr. GELLER. Mr. Libassi, who will be testifying next, is more expert in this area than we are. HEW has looked into the matter much more closely than we have.

We have tailored the bill so that we think it does not impose undue costs. Obviously, there will be some. We are now providing access to records, for example. We think people are entitled to have access to their records and have the ability to correct them. That may impose some cost, but we do not think it is inordinate.

The VA hospitals are already under the Privacy Act of 1974. Based on their experience, and based on the way we have tailored the bill so as to avoid most of the costly logging and accounting requirements of the Privacy Act, we believe that while costs will be incurred, they will not be inordinate. Rather, they will be reasonable.

I could go on, but I believe that Mr. Libassi is more expert on this and could discuss it better than I.

Mr. KINDNESS. Specifically with respect to VA hospitals, do we have any measurement we might apply for some degree of guidance here?

Mr. GELLER. We believe the experience of the VA and other hospitals has indicated no inordinate burden.

Mr. KINDNESS. I am not making my question clear, I guess.

I am speaking of objective rather than of subjective evaluations like those that have added so much cost to health care already because we sit here and say, well, it's not going to be undue or inordinate, but it is. That is one of the problems in the health care field today, these inordinate costs are rising out of legislative actions of this Congress and the regulatory actions pursuant thereto. I think we ought to be very careful to take any objective measurement that we have available to us as a guide at the present time.

I am just wondering whether now or later perhaps you would have any figures of an objective sort to submit for the record. We would very much appreciate it.

Mr. GELLER. I think there should be.

I did not mean to give you the impression this is all subjective. There is actual experience. That experience in numerical. It is concrete. That experience indicates that no new substantial personnel will be needed and that there will be no new recordkeeping requirements of a nature that would impose what you are talking about.

Clearly, some people would have to be trained. There will be startup cost. That has been looked at. We do not think that that would be inordinate in view of the experience with the Privacy Act.

The costs of the Privacy Act itself were greatly overestimated. I am talking generally. The costs turned out to be only one-eighth what they were estimated to be.

But again I say that Mr. Libassi, when he testifies, will be able to supply more concrete information on this score.

We are very sensitive to the problem of cost, though. We are aware of the importance of the issue you have raised. It is a very significant issue. We believe we have addressed it.

Mr. KINDNESS. Thank you.

In the other area, insurance information practices, the legislation as proposed would provide that individuals be notified of the information collection and disclosure practices of insurers. Would you expand a little bit on what is actually proposed there as to who would be informed and by what means of notice? I am thinking, for example, of what we experienced with the necessity for amending the bill passed last year with respect to banks giving notification on too broad a basis, whether we might be considering looking very closely at the notice requirements in this situation.

Mr. GELLER. Certainly we would be glad to do that. You do not have the bill in front of you now. There is no bill. We are still working on it.

On one of the reasons we are still working on it is to insure that there are no—you could use the word “glitches” or whatever. There are no gremlins of the nature that you refer to that occurred last year.

We are going to the insurance industry as well as to other groups and saying, “Here is what we propose to do. Is there anything you see here that would cause an inordinate burden, such as having to notify all past depositors?”

Essentially, what we are talking about here is, a situation in which when you go to purchase insurance, the insurance company would tell you, “Here is the information we need, and here is how we are going to go about collecting it.” You, as an individual will then know, for example, if the company wants to run a check on your lifestyle, if it wants to talk to your neighbors and all that. It will then not come as a surprise that the company is checking.

We are on the second draft of the bill. We will check it out carefully with the industry.

Mr. PREYER. If the gentleman would yield a moment on that point.

You are not then talking in any sense of compromising the authority of the States to regulate insurance practices.

Mr. GELLER. No. Not at all. We understand the McCarron-Fergusson Act and recognize that this is an area for the State. We have not imposed any Federal intervention so far as implementation is concerned.

We are imposing Federal standards, now. A number of insurance companies want that. They do not want the welter of State regulations. They would like to have a Federal base line. That is what we are providing. But it will not be implemented by any Federal authority. It will be implemented by the State commissions, if they

wish to do so. Or, in any event, the individual who will be given this Federal right will be able to implement it in court.

Mr. KINDNESS. Thank you, Mr. Chairman. I think my time has expired.

Mr. PREYER. Mr. Weiss?

Mr. WEISS. Thank you, Mr. Chairman.

I have, I guess, basically a philosophical question. I am interested in the framework with which the administration approached this subject. The opening statement of the chairman indicated how complex this whole area is.

I wonder whether, in fact, the administration approaches the subject basically from the point of view of the right of privacy of individuals or from the point of view of the access to information on the part of the Government. It seems to me that the approach that one takes really will determine what kind of legislation one will come up with and what kind of enforcement or implementation of that legislation one comes up with.

Mr. GELLER. I think that is an excellent question. I believe that we approach it by striking a proper balance. There is a clear need to redress the balance now. The individual right of privacy has eroded. The philosophy behind this policy initiative is to give the individual rights. So, we begin with that.

We do not want, however, to give the individual rights of such a nature that we completely close down to the Government the flow of information that is appropriate for the Government to get. For example, the Government does need information in criminal prosecutions. The question is, how does it get it?

Today, before this, it was getting it by simply walking in, flashing a badge, and saying, "I'm from the FBI; give me the information." They were getting it.

We believe that that is all wrong. The Government has a right to try to obtain information that is relevant to criminal or other suits, but the individual ought to be notified. A court should be involved if the individual wishes to contest. And the court ought to be the agency that says, "Yes, this is relevant. This is proper. This personal information should go to the Government." And it should not be decided simply by a bank, an insurance company, or a hospital without regard to the individual's rights.

So, we have tried to strike a balance here. The balance is one that redresses the rights of the individual in an appropriate fashion.

Mr. WEISS. In the example that you cited, for example, are you saying that the legislation which the administration supports and proposes would require that in all instances where the law enforcement agency is seeking medical records in regard to assistance in the prosecution of a case that, in order to be able to have access to that information, there has to be an application made to a judge, to a court with notification of that application being given to the individual whose records are being sought? Is that without doubt or without any question the premise of this legislation?

Mr. GELLER. The premise of the legislation is that the individual will be notified that information from his records is being sought and that the individual will have the right to go to court and

contest this. There are certain exceptions to this: fleeing the country, for example.

The difference is that, in the old days, the information could pass and the individual would not be aware of it. The premise now is that, with very narrow exceptions, the individual will be notified beforehand and will be able to contest the transfer of data.

In any event, at some point the court—even in the narrow exceptions—must be notified of what has occurred; and the individual must be notified.

So, what we have done is brought accountability to the process, brought the court in, and brought sunshine in. You can no longer harass an individual for political reasons or for anything of that nature. There is now accountability in this process.

These rights are spelled out in the Right to Financial Privacy Act and others; there are some narrow exceptions. But, for the most part, even for those exceptions there is still this accountability. The court must be notified. The individual must eventually be notified, although there can be delays of 90 days in certain cases.

Mr. WEISS. Of course, the individual always has had the right to contest the prosecution's utilization of any information which was improperly or illegally gained by moving to quash that evidence or to prohibit its utilization against him in a course of trial. The question, I guess, really is whether, in the guise of giving him additional protection, the Government may in fact not be authorizing the taking away of some of those protections.

Mr. GELLER. Before the 1978 act, the individual had no cognizable interest, had no legal right. The same is true for the fields we are considering here, such as insurance. The records are not his. I refer to the situation with a bank, for example, before the 1978 act or today with insurance records. You would have no right to prevent the insurance company from giving your records to a Government agent when he walked in.

We are changing that. An individual would now have a legal right. The insurance company could not turn those records over. There would be an expectation of confidentiality. The only way the company could turn them over would be if the Government used certain process. That process results in notification to the individual and his right to contest.

As I say, there are some very narrow exceptions. One pertaining to foreign intelligence and there are some other ones; but they are very, very narrow and constrained. Generally speaking—and I am talking now about 99 percent or something of that order—what I have said is correct: The exceptions are very narrow.

Mr. WEISS. You have been focusing on insurance and bank records. Does that apply also to medical records, health records?

Mr. GELLER. Yes. The bill which you have before you provides that general principle.

Mr. WEISS. In the area of the exceptions, who makes the determination as to whether the exception applies or not?

Mr. GELLER. A Government official would make that determination. But in many instances he has to support it by reporting to the court that he has done it, that he has gone in and obtained the information, the reason why he has obtained the information—perhaps he feared destruction or perhaps the person in question

was going to flee the country, or something of that nature. The official has to show his reasons to the court.

If it turns out that the matter has been handled improperly, there are penalties. If a court finds that it was done in bad faith, the office of personnel management must then consider disciplinary action other than penalties, actions such as liquidated damages, actual damages, and punitive damages obtainable by the individual for violation of the act.

Mr. WEISS. I appreciate your testimony. I think that, as far as the thrust or the aim is concerned, probably there is no question about the motivation. I think the reason why I have some questions about how it ultimately gets implemented is because I think back, for example, to the electronic surveillance legislation which started out in principle to prohibit or to reduce the amount of electronic surveillance. When you read the legislation, especially when you see its implementation, you see that, in fact, there is hardly anything that is excluded. Even those areas which originally were included are now being eroded either by the courts or by further legislative action.

So, I am always concerned that, when in fact we attempt to enhance people's rights or to spell out rights which they have under the Constitution, that we not end up, as we very often do, in taking away some of the rights which they still had before that legislation went into effect.

Mr. GELLER. I do not think we have done that. I am sure we have not taken away any rights. I think we have markedly improved the situation.

I would stress to you again that we have brought sunshine into this situation. We have brought notice. We have brought accountability. We have brought the courts in. That is very desirable, we believe.

Mr. WEISS. Thank you very much.

Thank you, Mr. Chairman.

Mr. PREYER. Mr. Erlenborn.

Mr. ERLENBORN. Thank you, Mr. Chairman.

Mr. Geller, are you here testifying on behalf of the administration that at the present time there is widespread abuse of confidentiality in medical records?

Mr. GELLER. No, we are not. The matter does not, we think, turn on showing of abuse.

There have been some abuses, I am told; but I do not know how widespread they are and I am not an expert in the problem.

Mr. ERLENBORN. You are not bringing us any horror stories as justification for our action?

Mr. GELLER. No. I am not coming before you with any horror stories. It may be that Mr. Libassi can point to some examples of abuse. I am sure they exist.

I want to emphasize that we do not think the matter turns on a showing of abuses. It turns on doing what is right.

Everything harmful that may be done in these privacy situations may be done in the most well-intentioned fashion. Hospital officials may turn over information about hospital records to Government agents or State agents or others in the most well-intentioned fashion. But we are saying that this is very sensitive information. The

individual should have rights about its dissemination. The Government should get such information only after notification and after certain process.

There ought to be an expectation of confidentiality so that it is not the hospitals' information to give out as they wish. We do not say that they are doing it, but there ought to be rights built into the situation.

Mr. ERLNBORN. In effect you are saying that this is something it would be nice to do?

Mr. GELLER. Not nice to do but it——

Mr. ERLNBORN. Let's say that is a given; we accept that. It is something that would be nice to do. The next question I have is, What argument do you have that it should be done at the Federal level?

Mr. GELLER. Again, we are speaking of medical records; this is Mr. Libassi's area. There is some State legislation here, but not all States have laws.

And, the information can be removed from one State to another, and that indicates a need for Federal law.

Also, the States cannot impose any obligation with regard to Federal officers seeking information. Only the Federal Government can do that.

There are a number of reasons why there ought to be this Federal base line. Without it, the personal information will be shifted around, and you will get this mish-mash of some States saying this and others saying that.

This bill does not set aside State legislation. If there is State legislation that is, for example, more stringent, it will continue to——

Mr. ERLNBORN. If it is less stringent?

Mr. GELLER. If it is less stringent, this bill provides a base line. This Federal one would hold, and it would——

Mr. ERLNBORN. You mean the institution may have two laws that they have to follow?

Mr. GELLER. Whatever they——

Mr. ERLNBORN. There is no preemption?

Mr. GELLER. They would have to follow the Federal law. If the State law is more stringent, they will continue to follow it as they do today; we do not preempt the field.

Mr. ERLNBORN. Well, you know, what is more stringent, what is less stringent is sometimes a matter of judgment. It is not just easy to say 50 percent, 60 percent, 70 percent. There may be different ways of doing something to achieve the same end.

You are telling us that this proposal does not preempt State law——

Mr. GELLER. It does not.

Mr. ERLNBORN. So that the institutions may have two laws to follow: The State and the Federal.

Mr. GELLER. The VA hospitals already must adhere to a great deal of these privacy requirements under the Privacy Act—but not to all of them. But the hospitals may very well also have to meet a higher State standard if such a standard exists. That means, as I say, that these institutions are following two laws today. If they

are, then the Federal standards may not affect them at all because they are less stringent.

Mr. ERLNBORN. I'd like to comment on your basis for legislative action. Because something would be nice to be done and not all the States have done it really does not seem to me to be a good argument for having the Federal Government do it unless we have some unique jurisdiction or reason to at the Federal level.

I have heard the argument—often coming from the business community; and you suggested that earlier in answer to one of the questions—it would be nice to have one standard nationwide. That argument, of course, leads me to believe that what we possibly ought to do is to abolish the State legislatures. We could do all the legislating here. We would have national standards everywhere. It would be so much handier. Nobody would have to wonder from one State to the other what laws you had to follow because we would not have all of those bothersome State laws standing in the way.

Do you think that there is really a justification in this area to accept that argument that it would be nice to have national standards?

Mr. GELLER. I think that there is a very strong justification. We are dealing here with the fundamental rights of individuals to privacy. The erosion of this privacy is occurring nationwide. The computers, the telecommunications links are all nationwide. We think therefore, that the Federal Government and Congress should move to correct this.

We are talking about an issue on which all people, I would think—liberal, conservative, whatever persuasion—could all agree. What has made this country remarkable is how it treats the individual.

Mr. ERLNBORN. If that is really true, I would think that you would argue for the preemption then.

Mr. GELLER. Well, if the State wishes to go further and afford even more stringent rights—we had not looked at all these laws; we are not—

Mr. ERLNBORN. Then we lose that nice uniformity, you see.

Mr. GELLER. But we are providing a base. And that is what is important because we are talking about such a fundamental right. All individuals—not just those in 21 or 22 States, but all of them—should have this fundamental right of privacy.

As to whether some of these laws are inordinately burdensome, we come back to what you yourself mentioned. That is we do not want to sit in judgment on each one of the State legislatures. If, in their wisdom, they have imposed some greater burden, we have not considered that. We do not know. We are not experts. And we have not preempted the field.

Mr. ERLNBORN. It is, I guess, a sign of the times of the last 20 or 30 years or whatever that we have decided something would be nice to be done and it ought to be done at the Federal level. But there are a lot of things that seem to be quite necessary like licensing drivers of automobiles, registration and licensing of automobiles, physicians, lawyers, any number of things that were good things and should have been done and were done by the States.

But in recent years it seems as though we do not have any faith at all that the States have the competency to do this. Or we are so

impatient that we cannot wait for them to do the things that are nice to be done. So, somebody comes along with a suggestion, "Let's do it at the Federal level; we will just impose that on the whole country all at once."

That is just an observation. You do not have to answer it.

Let me ask you this. I was interested as to the cost estimates. Did you crank into your cost estimates—or does Mr. Libassi crank into the cost estimates—the cost of the attorneys' fees for the institutions going into court to respond to the applications made by law enforcement officers?

Mr. GELLER. Again, I would have to leave that to Mr. Libassi. That is a difficult thing to calculate because you have to try to figure out how many suits will occur, and how many you think will be successful.

I think the only thing we can look to is the experience with the VA.

Mr. ERLNBORN. Well, I am kind of drawing on my experience, too, as a member of this committee back when the original Freedom of Information Act was passed. I have had something to do with the shaping of both the Freedom of Information Act and the Privacy Act. I have also been engaged in some of the oversight that this committee very wisely has conducted.

We found considerable expense on the part of the Federal Government in conforming to the legislation that we drafted out of this very subcommittee.

Let me put this to you. Let us say that we are not at all confident as to estimates of cost. Would you feel comfortable with a law that would allow a passthrough to the consumer of the cost that we impose on the institutions?

You know, we have the Federal Government on the one hand saying, "Let's have hospital cost containment." On the other hand it is legislating new things for the hospitals to do.

Would it not be fair to have a passthrough or an exemption from hospital cost containment of those new additional expenses, whatever they might be—minimal, not excessive, or maybe more than we anticipate—to allow the institution to pass that through without being caught between the devil and the deep blue sea with hospital cost containment saying you cannot raise your prices but the Federal Government saying you must do this or that?

Mr. GELLER. I just want to make one thing clear. There are many ways where a hospital would not get involved in the court process that you are referring to. For example, when the Government seeks individual records from a hospital, it is up to the Government to carry the burden. The hospital is left out entirely. The hospital gets a certificate from the Government that it has met the law's requirements and that is its protection.

Mr. ERLNBORN. The hospital may want to contest the Government's claim.

Mr. GELLER. It may, but I would—

Mr. ERLNBORN. I would hope in some instances they would.

Mr. GELLER. But I would think they would leave it very largely to the individual—

Mr. ERLNBORN. How about the passthrough?

Mr. GELLER. We believe that the costs involved here are not at all substantial.

Mr. ERLENBORN. Then you should not be afraid of a passthrough provision; should you?

Mr. GELLER. I do not understand how the passthrough provision would work.

Mr. ERLENBORN. It would exempt these extra costs from the hospital cost containment legislation that is being considered.

Mr. GELLER. It is not within my bailiwick. All I can answer to you is that it is beyond my power to make a comment on that.

Mr. ERLENBORN. I have one last question. I notice that you describe those institutions that would be affected by this Privacy of Medical Information Act as hospitals, other inpatient medical facilities, any outpatient clinic or facility receiving Federal assistance.

At first blush, that seems pretty reasonable until I remember what your organization, HEW, did with title IX—

Mr. GELLER. Not me.

Mr. ERLENBORN. Excuse me. You are not HEW.

It is what another element of our Government did with title IX of the education amendments, 1972, where Brigham Young University and a few other institutions that carefully avoided ever taking any Federal funds were found by HEW to be recipients of Federal funds because some of the students received Federal guarantees and loans or maybe basic educational opportunity grants, supplemental educational opportunity grants. So, of course, the long arm of the Federal Government got into Brigham Young and into a few of these other institutions.

Would a physician's office, because he has a medicare or medic-aid patient, be a facility receiving Federal assistance?

Mr. GELLER. No. The only thing that is done with regard to the physician is to impose a limitation on the Government when it seeks records that are in the possession of the physician.

Mr. ERLENBORN. What limitation do you have on this facility receiving Federal assistance? Do you say "directly"?

Mr. GELLER. Yes, if it—

Mr. ERLENBORN. In your proposed legislation does it say "directly"? Or does it allow the interpretation of an indirect receipt?

Mr. GELLER. I think it has to directly receive Federal assistance.

Mr. ERLENBORN. Could you cite that for me?

Mr. GELLER. Yes, we will find it.

Mr. ERLENBORN. I have found that people, especially in HEW, are able to interpret these things quite broadly to get Federal jurisdiction almost anywhere they want.

Mr. KINDNESS. Will the gentleman yield?

Mr. ERLENBORN. Yes.

Mr. KINDNESS. In the summary of the bill under enforcement—I guess it is the fifth page of the summary—there is reference to section 106: medical care facilities not in substantial compliance with the requirements of the draft bill—would be subject to removal from the medicare and medicaid programs and loss of funds under the Public Health Service Act and related laws. That gives us a little hint of what the gentleman is getting at, I believe.

Mr. GELLER. The question was asked about physicians. Physicians do not come under the bill other than to receive protection as to their files.

With regard to hospitals or with regard to other institutions that receive Federal assistance, they must comply. If they fail to comply, there can be a cutoff of Federal funds. Besides a cutoff, which may be very drastic, there are other remedies that affect the officials that are involved. But I repeat to you that there are ways that hospitals can avoid these liabilities. They can do this through the use of an institutional review board for access by researchers and by obtaining the certificate of compliance with Government access provisions. The hospital would be out of the picture entirely.

In answer to your question, I believe that the definition is in section 310. That section defines a medical care facility as any facility—including any Federal facility—but excluding any State or local facility that does not receive any Federal funds after the effective date of this act.

Mr. ERLBORN. It does not say directly or indirectly; does it?

Mr. GELLER. No, it just says excluding a facility that does not receive any Federal funds.

Mr. ERLBORN. Well, I am confident that there is not any medical facility in this country that you could not describe as receiving Federal funds directly or indirectly.

Mr. GELLER. It is repeated again: "If a facility is receiving funds from appropriations authorized by the Public Health Service Act," and it names other acts and I am now in section 310, "definitions" which talks about receiving funds from particular acts.

Mr. ERLBORN. Which would include medicare and medicaid—which probably covers every doctor in the country.

Mr. GELLER. Not doctors. Doctors are not covered at all.

Mr. ERLBORN. Are they excluded specifically?

Mr. GELLER. Yes. This bill does not lay any requirement or any obligation upon the physician. It deals with hospital—

Mr. ERLBORN. Does it define out—

Mr. GELLER. Yes. The only thing that—

Mr. ERLBORN. How about a clinic operated by several doctors?

Mr. GELLER. It would apply to an inpatient clinic if it were receiving Federal assistance, if it were receiving Federal funds.

But a particular physician would not be an outpatient clinic. But, if several of them, I gather, formed an outpatient clinic or an inpatient medical facility, the law would apply to them.

Mr. ERLBORN. I see on page 46 under definitions, it says "a health care provider is any person or any other entity that provides health services to individuals."

I do not want to press the point. Let us just say that I have raised it. Let us think about it.

Mr. PREYER. Mr. Libassi will be able to answer that.

Mr. GELLER. Mr. Libassi is more expert, but I believe the clear intent of the bill is that it should not lay obligations upon individual physicians.

Mr. ERLBORN. I am never satisfied with what we here think the intent may be. I have good cause to believe that our bureaucrats are very inventive in thinking up new ways to interpret the language we include unless we are quite specific.

Thank you, Mr. Chairman.

Mr. PREYER. Thank you. We will have some other witnesses that will be addressing these points.

I hope they will, when Mr. Libassi testifies, perhaps address themselves to this question. Mr. Erlenborn mentioned that there were no horror stories as justification for the medical records legislation. But I think there is a distinction between access to medical records and the abuse of that, which is widespread, and unauthorized use of the information which is obtained. Examples of that are harder to come by.

As I understand it, what you were telling us is that the unauthorized access to medical records is the real justification for legislation, that is where the erosion of privacy is occurring these days.

Mr. GELLER. Yes, sir.

Let me say that there are abuses. The bill, for example, provides that you cannot get this information through false pretenses. That has occurred. Insurance investigators pretend to be a doctor or something and gain access to records.

There was a case in Colorado where such false pretenses played a role. The Supreme Court of Colorado held that there was no legally recognizable right of an individual to keep his hospital records private. So, there have been abuses. The bill does deal with those abuses.

But your statement is correct, Mr. Chairman. What we are trying to do is redress the balance generally. Even if there were not those abuses, this type of sensitive personal information is something the individual should have rights about, to have protected. A hospital should not be able to give out its records as it wishes. There ought to be an expectation of confidentiality, a legal right to preserve that confidentiality.

Mr. PREYER. He should have that right even though a hospital never sold that information improperly to a credit agency or something like that?

Mr. GELLER. I am sure that most hospitals are acting very responsibly. Nevertheless, there should be that right.

Mr. PREYER. Thank you.

Mr. Kostmayer.

Mr. KOSTMAYER. Thank you, Mr. Chairman.

I am rather puzzled by the views expressed by my distinguished colleague from Illinois. These are presumably rights which are granted to all Americans, regardless of what State they happen to live in. We have a Federal Constitution which grants rights upon the basis of American citizenship, not upon the basis of what State you happen to be a citizen of.

I think these protections are important. I know that gentleman is a distinct conservative and cares, as I do, about the rights of individuals, so I am puzzled at his views.

Mr. Geller, I wanted to ask you to straighten something out for me if you could. It is my understanding that the administration is supporting legislation which would overturn the effect of the *Stanford Daily* decision. Is that right?

Mr. GELLER. That is correct.

Mr. KOSTMAYER. It is my understanding also that the Department of Justice did file with the Supreme Court at the time that

case was heard a friend of the court brief supporting the eventual ruling which you now seek to overturn. Is that right?

Mr. GELLER. That is correct.

Mr. KOSTMAYER. Is that a contradiction or simply a change of policy?

Mr. GELLER. Mr. Heymann, the Assistant Attorney General, stated that, whatever the constitutional issue—and the issue before the Supreme Court was one of constitutional law and involved construing the first and fourth amendments—the Court in that case did invite the Congress and, correspondingly, the administration to look at it from the point of view of policy. The administration did look at it from the point of view of policy and concluded that the policy embodied in the *Stanford Daily* decision could have a chilling effect upon the press in many ways. You are familiar with those considerations.

Therefore, the administration said, as a matter of policy, let us urge Congress to take steps to redress the situation.

So I think the difference is between what is the constitutional requirement and the requirements the Congress can establish as a matter of policy.

Mr. KOSTMAYER. In any event, you are opposed to the ruling of the court and support legislation to overturn its effect?

Mr. GELLER. The effect of the ruling is unfortunate because it does erode the rights of people engaged in disseminating information to the public. It is very important to take remedial action. That is why the administration has proposed such action.

Mr. KOSTMAYER. It is my understanding—again, correct me if I am wrong—that telephone records are not included under this legislation. It would still be possible, for example, for the FBI to go, in my case, to Bell of Pennsylvania and obtain my telephone records without my consent or my knowledge.

Is that correct?

Mr. GELLER. That is correct. But the reason why telephone records are not treated in this legislation is not that there is no serious privacy issue raised by access to these records. We agree that there is. But a case is now pending before the Supreme Court. It was argued last week. In that case, it has been urged that obtaining such records without a search warrant violates the fourth amendment.

We are awaiting the decision in that case before we consider again the privacy issues involved in this situation. We do not disagree that there are substantial privacy issues involved in telephone toll records.

Mr. KOSTMAYER. Apparently that is the position of the Department of Commerce. But I gather it is not the position of the Department of Justice. Mr. Civiletti was before our subcommittee some time ago and expressed a view which I think is contrary to yours. I do not want to speak for him, although I am. He expressed the view that the Federal Government did have a right to obtain these telephone records and that there was not a fundamental issue of privacy concerned.

I would hope that you would, pending this decision that you are speaking of, address the situation. It seems to me there is very little difference between these types of records whether they are

insurance records or employment records—which I understand are not covered also generally; employment records. I guess insurance records are. In some cases academic records are. Telephone records are not.

In that sense, I think the administration's proposals are woefully inadequate and do not go nearly far enough in including telephone records. So, I hope you will consider that.

Mr. GELLER. We will certainly consider the issue of telephone toll records. It is an important privacy issue. As I say, after the Supreme Court's decision, we will have to consider it. We agree with you that it raises very serious issues.

Mr. KOSTMAYER. I hope you will speak with Mr. Civiletti and straighten him out about that.

The *Stanford Daily* legislation apparently does not cover third parties, as the subcommittee, as you know, recommended; it only covers newsmen and certain professionals under your proposed legislation. Can you explain that omission?

Mr. GELLER. That decision was made because the area is troublesome. It is troublesome, I am told, from a constitutional point of view. It is troublesome also because very often third parties have very close connection with alleged criminal activity. Therefore, these third parties can become in a manner of speaking, sanctuaries or havens in which information could be stored and which could not be searched.

Mr. KOSTMAYER. Would not it be better to err on the side of being too fair and too equitable rather than on the side of the Government?

Mr. GELLER. I can only state that the Department of Justice, which looked at this and is the expert agency thought that it raised great difficulty. Even when they evaluated doctor-lawyer or other particular relationships, they found it was difficult to draw the line: What would you put within, what would you leave out?

The step was taken here because it is so important in the first amendment area. That was defined very broadly as all those engaged in disseminating information to the public.

To carry it further and apply it to all third-party searches raises, as I say, the issue of sanctuaries. It raises two constitutional issues.

For that reason, it was decided that, while the area deserved further study, it was not appropriate to weight down this particular legislation with that type of difficulty.

You recall that, after Brandenburg, because of all the various issues, nothing was done. It may have been unfortunate, but no legislation was passed. The area may be satisfactorily taken care of now under the Attorney General's guideline.

But I think, as a matter of policy, it was decided to focus on the essential first amendment area and not to try to broaden it to cover everything and perhaps end up with nothing.

Mr. KOSTMAYER. Would you agree that because of that the burden of protecting one's privacy is now on the citizen rather than on Government?

Mr. GELLER. In the third-party area? There is certainly no protection being proposed by the Government in that area. The law as it stands today is the *Stanford Daily* situation. That case would still

be applicable in the case of third-party searches. It did not involve this first amendment area.

Mr. KOSTMAYER. Again, I think that your proposals are good. I sympathize with them. But I think in this regard, as well as the area of telephone records, that they really do not go far enough; and they are inadequate. I think generally, if we are going to err, we should on the side of individual privacy rather than on the side of the Government.

Thank you, Mr. Chairman.

Mr. PREYER. Let me suggest at this time that we ask Mr. Libassi to join Mr. Geller, and I hope Mr. Geller will be able to stay with us a little longer.

Mr. Libassi is general counsel of the Department of Health, Education, and Welfare. His statement will relate primarily to the medical records provision, an area in which we have already had some questions.

Mr. Libassi, your statement will be made a part of the record, without objection. You may summarize it or any particular aspects of it that you wish.

STATEMENT OF PETER LIBASSI, GENERAL COUNSEL, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE; ACCOMPANIED BY DARREL GRINSTEAD, ACTING ASSOCIATE GENERAL COUNSEL

Mr. LIBASSI. Thank you, Mr. Chairman.

My name is Peter Libassi. I am General Counsel of the Department of Health, Education, and Welfare. I am accompanied by Mr. Darrel Grinstead, the Acting Associate General Counsel of the Department.

Mr. Chairman, I would particularly like to thank the committee for the opportunity to present the Department's and the administration's views. I would also like to thank Mr. Geller for so graciously absorbing the committee's heat. There may be a little left for me, but I do want to thank him for that.

I will now review some of the issues.

President Carter on Monday of this week sent to the Congress a message outlining a comprehensive national policy to protect the privacy of individuals in this age when personal information is increasingly available. The protection of the privacy of medical information is an important part of the President's overall proposal.

The President's initiative is based in large measure on the recommendations of the Privacy Protection Study Commission, established by Congress to study the information systems including those in the health care field. We believe we have struck the proper balance between the often conflicting needs for privacy and the needs for information.

The information in medical records is uniquely personal. To enable physicians and other health professionals to make diagnostic and therapeutic decisions, a patient must often reveal intimate personal matters. Medical developments have increased the volume, complexity, and sensitivity of the personal information in medical records.

At the same time, social and technological developments have weakened the traditional protections for the confidentiality of this information. The physician's ethical standards have traditionally protected the patient's confidences. State legal protections, such as the physician-patient privilege, have provided additional protection.

But now health care is often provided in a more impersonal setting. Traditional ethical standards and controls on access to patient records have been greatly eroded. The computer, of course, has contributed in large measure to this problem.

The administration has therefore concluded that legislative protections are needed to supplement these traditional protections. Our proposal provides for the basic protections that all our citizens ought to have with respect to their medical records. The maintenance, use, and disclosure of medical information has become a national business. It requires the comprehensive, systematic approach that can only be provided by Federal legislation.

Our bill follows the basic principles which have been outlined by Mr. Geller. First, it is to establish a code of fair information practices for the holders of medical records and, two, to place limits on Government access to private medical information.

Title I of the bill provides that medical care facilities must treat information which they maintain about their parties under certain specific prescriptions. It would cover all hospitals and all nursing homes. In short, it would cover all inpatient facilities. It would also cover, to the extent provided by regulations issued by the Secretary, that outpatient facilities which receive funds under particular Federal programs would be covered.

This title would also cover Federal hospitals. The Privacy Act would be amended so that disclosure and patient access provisions of this act would replace those of the Privacy Act for Federal hospitals.

Hospitals operated by State and local governments which do not receive Federal funds would not be covered.

Under the bill, patients would be able to see their records or designate others to do so for them and would be able to obtain copies of materials in their files. Since there may be instances in which prudent medical judgment concludes that direct access by the patient would be harmful, the bill authorizes the medical care facility to channel that record through a third party designated by the individual.

A patient would now be permitted under our bill to seek correction of his medical records. The facility would have to make the correction or permit the patient to file a concise statement setting forth the patient's view.

The administration's proposal establishes an expectation of confidentiality for medical records. Disclosure of information about a patient is prohibited unless the patient consents or unless the disclosure falls within certain specified exceptions.

The disclosures permitted without consent fall into four general categories.

First is the disclosure in the normal operation of the institution as part of its daily procedures, or when needed for the patient's

care, or a close relative wishes to have access to the information about the patient.

The second category deals with situations in which disclosure about the specific patient is needed but the patient's identity is incidental to the use of the record. Research, audit, and certain uses for payment programs fall into this category.

Third is disclosures which may affect the individual, but where it would thwart the purpose of the disclosure to seek consent, such as law enforcement purposes. Some of these disclosures have specific procedural safeguards to protect the rights of individuals.

Fourth is disclosures within the Federal Government, where consent requirements would create excessive administrative burdens.

We have given a great deal of thought, Mr. Chairman, to the framing of these nonconsent disclosures and the conditions surrounding them.

The Privacy Commission noted the tension between society's interest in protecting medical confidentiality on the one hand and its legitimate needs for access to medical records on the other. This conflict is not easy to resolve. However, we believe those exceptions we have suggested in the administration's bill are appropriate and will not unduly impinge on the individual's privacy rights.

I would like to speak to a number of these authorized disclosures which are necessary to achieve important societal goals.

Certainly no one can deny the need for health research, and our bill would preserve the ability of researchers to obtain needed information from medical records. At the same time, the bill would impose a number of obligations on facilities and researchers to assure that information, once made available for a research purpose, is not redisclosed to others for nonresearch purposes that may adversely affect the individual.

The Public Health Service and the Food and Drug Administration need information from medical records to fulfill their regulatory missions and to protect the public health. Federal and State health payment programs as well as private insurers need that information to administer and protect the fiscal integrity of their programs. Accordingly, under these circumstances, information would be made available without the patient's consent.

Patient consent is not feasible in many of these cases or it can be obtained only with extraordinary expense and delay. Since, in most cases, the patient is not the target of the inquiry requiring access to the record, the degree of protection required is somewhat less than if the Government is seeking information for purposes directly related to the individual.

We believe that the incidental risk to the individual's privacy presented by such disclosure is outweighed by the public's benefit in permitting it. The restrictions in the bill on redisclosure of medical information so obtained should adequately protect individual interests.

Title II deals with the limits of Government access.

Title II spells out the circumstances under which Federal and State authorities may obtain information from health records held by any health care provider. Let me emphasize here that title I deals with health facilities. It sets forth in title I the circumstances under which a health facility may disclose information.

Title II provides restrictions on the Government's access to that information, whether held by a health facility or by a private physician.

So, title II establishes limitations on the Government's rights to ask a private physician for access to a private medical record.

Title II is meant to protect the records of individuals served by anyone who provides health services including physicians, dentists, nurses, psychiatric social workers, and clinical psychologists, for example. This title does not impose new responsibilities on these providers. It does impose obligations on the Government authorities who seek access to these medical records.

Title II permits Government authorities to obtain information for research, audit, evaluation, medical emergencies, care of the patient, payment of claims, and other uses for which disclosure is authorized under title I.

The conditions surrounding such access are similar to those governing disclosure in title I. For example, a Government agency receiving information for research must give all assurances and is bound by the same restrictions on reuse that a private researcher would be bound by.

Attempts by Government agencies to obtain information by summons, subpoena, search warrants, and formal written request, under circumstances not otherwise permitted by the bill, would be subject to a number of procedural protections.

It is the purpose of these protections to assure that, where appropriate, the individual whose record is sought has an opportunity to be heard before a court. The authority would have to notify the individual in advance that it wanted the medical information concerning him. The individual would have an opportunity to challenge in court the authority of the Government agency to obtain his record.

These notice and challenge provisions could be waived by a court where prior notice would likely result in the destruction of evidence, flight from prosecution, physical danger to anyone, or would otherwise seriously jeopardize the Government investigation. Notice to the patient could also be waived in certain emergency circumstances if within 5 days of obtaining such access the Government agency filed in court a sworn statement setting forth the nature of the emergency.

As for enforcement, again Mr. Geller outlined the administration's general proposals with respect to enforcement. I would simply like to say that we want to avoid the necessity of creating new Federal enforcement mechanisms.

So, although Federal funds can be terminated where there is substantial noncompliance, the primary enforcement mechanism would be through private civil suits brought by the aggrieved individual in Federal or State courts.

We believe this enforcement approach is preferable not only because it will not require the expansion of Federal agencies and work forces, but also because the protection of privacy rights is uniquely suited to private enforcement.

With respect to the relationship to other laws, it is the intent of our proposal to permit all existing statutory and regulatory protections for the confidentiality of medical records to remain in force.

For example, the statutes governing the confidentiality of information on drug and alcohol abuse patients provide more stringent protections for these patients than our proposal does. These more stringent protections would be preserved.

I wish to pick up now on the question of burden on facilities.

In these days of rapidly rising health care costs, we believe it is important to minimize the administrative burdens on health care facilities. We believe we have designed these proposals with care to avoid unnecessary recordkeeping, notifications, and other paperwork. Likewise, we have avoided prescribing administrative procedures such as requiring appeals systems within a hospital.

This bill will permit medical care facilities to build on their existing recordkeeping procedures with a minimum of additional effort and expense.

In conclusion, let me say that the protection of the privacy of individuals with respect to medical information cannot depend solely on one statute or even a set of statutes. We need a strong commitment to the right of privacy and the careful design and management of record systems. These cannot be compelled by law. Nevertheless, sound legislation will provide the essential legal framework for the protection of individual privacy.

I would be happy now to answer questions from the members of the committee.

Mr. PREYER. Thank you, Mr. Libassi.

You have indicated the problems in striking a balance between privacy and all of the other public interests. It certainly makes for a more complicated bill. As the opening statement said with regard to Hippocrates, he said, "Whatever should be kept secret, whatever should be kept quiet, I will keep secret—period." Hippocrates, where are you now that we need you?

You alluded to the uniquely personal side of medical records, which may include information about alcoholism or sexual activity or psychiatric problems. Yet, I notice that you use the same standard as far as law enforcement agency access to medical records goes as is used in the Right to Financial Privacy Act, the same standard as is used with bank records.

Don't you think medical records are more uniquely private than bank records? Should we have a different standard between the two?

Mr. LIBASSI. It is the administration's position at this time, Mr. Chairman, that we should consider a uniform set of standards and test these, explore with the committees of Congress the appropriateness of these standards, and proceed with them on a uniform basis for the time being.

Should the experience dictate that there ought to be some modification, we should consider it. But we have to remember that there are serious law enforcement problems requiring access to medical records, particularly in the prevention of fraud and abuse in Federal programs where extensive Federal funds are available to finance the care being provided to patients. On that basis, we feel that it is essential that we preserve access to these records on the same basis as we do for the other areas.

Mr. PREYER. But you do make an exception for fraud and abuse access to the records, I believe, in the bill?

Mr. LIBASSI. Yes—

Mr. PREYER. Generally speaking, there is not the general law enforcement need to have access to medical records as there is in bank records, is there? There is a government need to check fraud and abuse using medical records, but hardly a general law enforcement need; is there?

Mr. LIBASSI. You are correct, Mr. Chairman. I agree with you that the general law enforcement programs perhaps are in greater need for financial and banking records than they may be of medical records. But the Federal Government and State Governments do have substantial need for access to these records in connection with the programs which are now funded by the Federal Government.

Mr. PREYER. I gather then that your position is flexible. You will wait and see how it develops, whether the law enforcement standard applying to bank records should be the same as that applying to medical records?

Mr. LIBASSI. Yes, Mr. Chairman.

Mr. PREYER. Mr. Kindness made the good point earlier today that we should benefit by concrete examples of ongoing programs. Under the Privacy Act, individuals are allowed to inspect medical records maintained by Federal agencies.

I wonder what learning we can get from that. Has HEW implemented any special procedures to implement that provision? What has been our experience with that?

Mr. LIBASSI. The experience of the Department to date has been positive, Mr. Chairman. Records held by HEW hospital facilities have now been made available to the patients, so they have an opportunity to examine their own records.

Mr. PREYER. Have many people taken advantage of that opportunity?

Mr. LIBASSI. There have not been the number of requests by patients to examine their own records that was anticipated when the legislation was first considered. For instance, at the NIH clinical center we have 115,000 records, and we had 400 requests in calendar year 1978. That is a little more than one request per day for the opportunity of patients to examine their records.

At PHS hospitals and clinics we have over 6 million records. We have had about 10,000 patients who had requested an opportunity to examine their records.

At St. Elizabeths Hospital, we have a situation in which we had only 44 requests for patients to examine their records. But we believe that is because the patients are apprised of their records, and their records are used as part of the treatment program. So, that may be an unusual situation at St. Elizabeths.

In our New Orleans Hospital, which is a 300-bed hospital, we have had only 10 requests a year from patients for an opportunity to examine their records.

So, the requests of patients to examine their records has not been inordinate. At the same time, I would say that it is a positive part of the patient's treatment program to have access to their records. As you are well aware, Mr. Chairman, the access to patient records is not uniform across the country. In many States,

there are no provisions to assure patients that they can have access to their own records.

Mr. PREYER. How about the history of withholding records from individuals because of concern that it might have unfortunate consequences, perhaps medical consequences, to the individual? Are there any lessons to be learned about how widespread that is or whether that is a problem?

Mr. LIBASSI. We do not have statistics, Mr. Chairman, on the number of requests which have been filled through third parties other than the reported impressions to us that this is rare, quite infrequent, and that, generally speaking, the information is made available directly to the patient.

Mr. PREYER. Thank you, Mr. Libassi.

Mr. Kindness.

Mr. KINDNESS. Thank you, Mr. Chairman.

Mr. Libassi, I noticed that in title III general provisions, section 301, it would create a new crime, a misdemeanor with respect to any person who under false pretenses requests or obtains medical information concerning an individual from a health care provider. It says he shall be guilty of a misdemeanor and upon conviction shall be fined no more than \$10,000 and not more than one year imprisonment.

Could you explain to us the thought process or the judgmental process involved in arriving at that proposal? And does it relate to any other existing statutory provision with respect to penalties on a comparative basis?

Mr. LIBASSI. I am not able to answer the second part of your question as to how this section of the law relates to other sections. I do not know whether or not we have any additional information on that in terms of where this type of penalty may exist in other statutes.

If I can, I would like an opportunity to submit for the record a memo on any other Federal laws with similar provisions.

[The memo follows:]



DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
OFFICE OF THE SECRETARY
WASHINGTON, D.C. 20201

APR 19 1979

OFFICE OF THE
GENERAL COUNSELOFFICE OF THE GENERAL COUNSEL
LEGISLATION DIVISIONMEMORANDUM

TO : Peter Libassi
General Counsel

FROM : Darrel Grinstead
Attorney Advisor

SUBJECT: Obtaining Medical Information Under False Pretenses

RECEIVED
APR 24 1979
AM 7 8 9 10 11 12 1 2 3 4 5 6 PM

When you testified on April 4, 1979 before the Subcommittee on Government Information and Individual Rights of the House Committee on Government Operations on the Administration's proposed Privacy of Medical Information bill, you were asked whether there were other Federal laws comparable to section 301 of our bill, which would make it a misdemeanor for anyone, under false pretenses, to request or obtain medical information concerning an individual from a health care provider. This memorandum addresses that question.

The model for section 301 is contained in the Privacy Act of 1974, 5 U.S.C. 552a(i)(3) which provides as follows:

(3) Any person who knowingly and willfully requests or obtains any record concerning an individual from an agency under false pretenses shall be guilty of a misdemeanor and fined not more than \$5000.

The authority of the Federal Government to impose criminal penalties for such an offense is, of course, based on the fact that the records covered by the Privacy Act are in the hands of a Federal agency.

Both the Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment and Rehabilitation Act of 1970 and the Drug Abuse Office and Treatment Act of 1972 have provisions designed to protect the confidentiality of the records of any patient maintained in connection with

the performance of any alcohol or drug abuse prevention or treatment activity "conducted, regulated or directly or indirectly assisted by any department or agency of the United States." (21 U.S.C. 1175 and 42 U.S.C. 4582) Both of those statutes contain criminal penalties for violations of those confidentiality provisions. (21 U.S.C. 1175(f) and 42 U.S.C. 4582(f))

However, unlike section 301 of our proposal, the reach of the protections in the alcohol and drug abuse acts is only with respect to records for which there is some connection with the Federal Government.

Section 301 goes beyond the above described provisions and would impose Federal criminal penalties on anyone who requests or obtains medical information about an individual under false pretenses, regardless of whether there is any Federal interest in the records. Our proposal for criminal penalties for this offense is based upon the finding that the practice of obtaining medical information under false pretenses affects interstate commerce and is therefore within the reach of Federal power.

The closest analogy to our proposal in other areas is the Fair Credit Reporting Act which contains the following criminal provision in section 619:

Any person who knowingly and willfully obtains information on a consumer from a consumer reporting agency under false pretenses shall be fined not more than \$5,000 or imprisoned not more one year, or both. (15 U.S.C. 1681q)

This provision is based, presumably, on the effect of consumer credit reporting practices on interstate commerce. See section 602 of the Fair Credit Reporting Act, 15 U.S.C. 1681. */

*/ The term "consumer reporting agency" is defined in 15 U.S.C. 1681 a(f) as any person engaged in assembling or evaluating consumer credit information and "which uses any means or facility of interstate commerce...."

While our proposed section 301 does not require a showing of any effect on interstate commerce to establish a violation, it is clear from the Report of the Privacy Protection Study Commission that the safeguarding of the confidentiality of medical records is an interstate problem. See Chapter 7 of the Report of the Privacy Protection Study Commission, Recommendation (4), p. 294. We expect the Congressional hearings on this proposal to uncover additional evidence of the effect on interstate commerce of confidential medical information obtained under false pretenses.

The Supreme Court has upheld criminal statutes based on the interstate commerce clause, even where there was no showing of an effect on interstate commerce in the particular case before the Court. In Perez v. United States, 402 U.S. 146 (1971), the Court upheld an anti-loan sharking statute, 18 U.S.C. 892, on the basis of Congressional findings, reflected in the legislative history of the statute, that extortionate extensions of credit affect interstate commerce, principally through the support such practices provide for organized crime. The Court observed at 402 U.S. 154:

Extortionate credit transactions, through purely intrastate, may in the judgment of Congress affect interstate commerce.

Therefore, it is reasonable to conclude that, if the legislative history of the privacy of medical information legislation demonstrates that obtaining medical information under false pretenses affects interstate commerce, a provision such as section 301 would be found to be within the legislative power of Congress.

Mr. LIBASSI. As you point out, Mr. Kindness, this provision does make it a crime for an individual to obtain information under false pretense. What is intended here is to protect against a situation where an individual goes to a private physician, pretends to be a law enforcement officer or pretends to be an insurance company representative, and on that basis asks the private physician for information. The private physician, relying on the representations of the individual, makes that information available.

At that point the person who has requested and secured that information would have been guilty of a crime.

The law does not place any obligations on the physician. It does not require the physician to disclose that information. But, if the physician should, the individual who sought that information would have committed a crime and would be subject then to these penalties.

Mr. KINDNESS. I have a preoccupation these days with the efforts to codify the Federal criminal laws. I am having a little difficulty fitting this into the context of any of the proposals exactly for criminal code.

We are talking only about false pretenses and only about health care providers and not about health care facilities. I am trying to get the Federal connection that is presumably necessary to establish such a misdemeanor.

We are not necessarily talking about interstate commerce. So, we do not hinge it on the commerce clause. What is this hinged on?

Mr. LIBASSI. Mr. Kindness, let me say first that a health care provider includes, by our definition, a health care facility as well as the private physician's office. So, if anyone went to a hospital or a physician's office or a dentist's office, they would be covered; they would have committed the same offense.

On page 46 of the bill, we define health care provider to include all medical care facilities as described above as well as any person providing health services.

I think we would like an opportunity with the Department of Justice to consider further this issue. And this may be modified. When the criminal code revisions are worked on by the Department of Justice and the Congress, this particular section may be modified. So, I am not in a position to——

Mr. KINDNESS. Oh, it will be.

Mr. LIBASSI. I think we would want to reserve with you the opportunity to discuss how this provision and the criminal code provisions then might be made to conform.

I did want to indicate that there are standard procedures in which anybody misrepresenting themselves to any health care provider or facility would be subject to these penalties.

Mr. KINDNESS. Thank you.

Then, in the following section on civil suits, some new law is proposed whereby there would be a right to bring an action in a U.S. district court without regard to the amount in controversy or in any other court of competent jurisdiction.

I am uncertain as to whether a State court would be a court of competent jurisdiction with respect to this particular proposal if it became statutory law. Let us assume for the moment that most of the cases would be brought in Federal courts. We are establishing

some new concepts really in the proposal here as to what damages would be recovered. All actual damages—as a matter of fact, the language at the bottom of page 41 of the bill says that a violator shall be liable to the aggrieved individual for all actual damages sustained by the individual. Then it goes on to provide for sort of punitive damages of not less than \$100 nor more than \$10,000.

Could you give us the rationale for including this provision in the bill?

Mr. LIBASSI. Mr. Kindness, it may be difficult to establish the actual damages for the invasion of a person's privacy. It might be argued that it was of no consequence that his privacy was invaded, that he suffered no monetary damage, he lost no time at work, he has not been publicly humiliated. Therefore, the right to protection from invasion of one's privacy would be undermined because there was no way to impose a sanction on the organization or institution that improperly invaded the privacy.

A researcher who rediscloses the information to other persons for inappropriate reasons could come in and, as a defense, say that there is no damage suffered. So, the general damage provision was added as a way of attempting to put some teeth into the protection of the rights of privacy of the individual.

Mr. KINDNESS. This is presumably going to include the United States of America, the States, perhaps local governmental entities conceivably. And these actions can be brought against these governments as well as individuals.

Am I correct?

Mr. LIBASSI. Yes, sir.

I believe, where a State has waived its sovereign immunity, then the State would be subject to these proceedings. Where it has not waived its immunity, then the officer or employee would be subject to suit.

Mr. KINDNESS. By passing this law, we would not be saying somehow that the States were deemed to have waived their immunity?

Mr. LIBASSI. No, sir.

Mr. KINDNESS. Thank you.

Thank you, Mr. Chairman.

Mr. PREYER. Mr. Weiss.

Mr. WEISS. Thank you, Mr. Chairman.

Mr. Libassi, in your listing of the exceptions, I think the last exception that you stated was something to the effect that, where failure to have availability of those records would in essence injure the case that the Government had, or some such, could you go through that?

Mr. LIBASSI. These were the situations in which disclosure would be permitted?

Mr. WEISS. That is right.

Mr. LIBASSI. Without the patient's consent? The last one was disclosure within the Federal Government, where consent requirement would create excessive administrative burdens.

Mr. WEISS. No.

Mr. LIBASSI. Disclosure which may affect the individual but where it would thwart the purpose of the disclosure to seek consent. These are law enforcement purposes where there would be

some disclosure, but there would be specific procedural safeguards to protect the rights of the individual.

And then the second one was disclosure in which the specific identity of the patient may be needed but is incidental to the use of the record. That is in connection with research and audit.

And then the first one was, disclosure in the normal operation of the institution.

Mr. WEISS. I guess it was the third one then.

Mr. LIBASSI. Disclosure which may affect the individual but where it would thwart the purpose of the disclosure to seek consent. And that is basically law enforcement purposes where the individual either might flee the jurisdiction or the evidence might be destroyed. Then the law enforcement office could seek the information without consent of the individual.

Whenever the Government is seeking access for law enforcement purposes which are not provided for elsewhere in the bill, they must then go before a court and indicate why notice is not required.

Therefore, we are trying—as Mr. Geller indicated earlier—to establish ground rules that will govern how the Federal/State agencies secure information without consent. There are certain specific cases where they may seek it without consent. There are other cases where they must obtain consent.

If they feel there is some extraordinary reasons why they should not have to consent of the patient, they must go before a court; and the court must agree that they should have access to that information without the patient's consent.

Mr. WEISS. At one point I think there was mention of exception in instances of foreign intelligence? How is that formulated?

Mr. LIBASSI. The Central Intelligence Agency would have the right under the bill, where national security issues were involved, to gain access to a patient's medical record held by a facility or by a provider. The bill also provides that, where the Central Intelligence Agency seeks that information, the patient may not be advised of that fact by any of the employees of the facility or the provider.

So, there could be, under this bill, absolute secrecy in the access of the information by the CIA and no disclosure to the patient by anyone that they had access to the record.

Mr. WEISS. You mean that, if the CIA, for whatever reason—good, bad, or indifferent—decided that it wanted to get the records of the patient at a particular psychiatrist's office, it would have the right to go in and get that information without notifying the patient; and the doctor would have no right to refuse to turn the information over?

Mr. LIBASSI. I want to be careful on this. Under this law, no new obligation to disclose is provided. This law does not impose any new obligations on any facility or provider to make information available. If they are not required to make it available under some other law, they are not required to make it available under this law. This law only sets forth the procedures that should be followed in making the information available and the procedures that should be followed in seeking it.

So, if a physician or a hospital is not required to make the information available to the CIA, this proposed bill does not impose that obligation.

I am not in a position to say under what rules and under what circumstances the CIA has an absolute right to information. I cannot answer that question, and I do not know what statutes govern the CIA.

Mr. WEISS. In the course of an earlier discussion, Mr. Geller had said that there is no burden placed upon any physician in this legislation; that the only thing that is done really is to provide some protection to the doctor so that the doctor, if an FBI agent came along or someone else flashing a badge, would know that there is no mandate to turn over the information because this legislation specifically provided that information did not have to be disclosed.

Now what you are saying in essence is that that may very well be true, but, in the case of the CIA, the physician in that instance really would not have that built-in protection. Indeed, quite the opposition, implicitly, the CIA would have the right to demand that record; and the doctor would in essence be taking a gamble as to whether in fact he or she should or would have to turn those records over.

Mr. LIBASSI. Mr. Weiss, let me say that this statute requires that, if a Federal agent approaches a physician or a hospital on the grounds of conducting foreign intelligence or counterintelligence activities, they must provide to the facility in writing a certification that the document is needed for those purposes. That certification has to be signed by a supervisory official of rank designated by the head of that agency.

At that point the hospital or the physician may or may not turn over the information. This law does not require them to do that.

I do not know whether or not other statutes may. But, under the bill that is proposed by the administration, the hospital or the physician is under no additional obligation to turn that information over. They may demand from the CIA agent in writing that the agent certify that the information is need for these purposes. In fact, the Federal agent would be violating this statute if they went in and said, "I am a CIA agent; I would like so and so's record." They must provide written certification to the holder of the record that they are authorized by the head of the agency to seek that information.

So, in essence, what we are doing is placing a limitation on the Federal Government as to what circumstances and under what conditions it may seek medical records for foreign intelligence and counterintelligence activities.

This bill does not require the holder of the record to turn it over.

Mr. WEISS. Would you not think, Mr. Libassi, that, since there seems to be some vagueness about that whole area, and it apparently would require the physician to have an awareness of that fact that you have just stated on his own, that perhaps the legislation itself ought to specifically state: Provided, however, that nothing in this provision mandates any facility or physician to turn such information over to such agent unless otherwise required by some other law?

Mr. LIBASSI. I agree with you. Yes. If it doesn't, it certainly should.

I hope that I can find the section where it does. But, if we do not find it, I would agree with you that it ought to make it explicit that this statute does not impose any new obligations to disclose.

Mr. GELLER. May I add to Mr. Libassi's answer? There is an annual tabulation of all such requests. These are, as he said, exemptions from procedures. When the process is used, when the certificate is given, there is to be an annual tabulation of the occurrences submitted to the appropriate congressional committees either by the Secret Service or by the foreign intelligence agencies, such as the CIA.

So, it does go to the Congress. The Congress has oversight in the area of what is going on.

Mr. WEISS. Mr. Geller, with all due respect, that same requirement exists as far as the electronic surveillance legislation is concerned. But, if those records indicate anything at all, it is that invariably—I think just about 100 percent or 99.999 percent of the time—the application is granted.

I do not know what that recordkeeping really does as far as providing protection for the individual patient or the individual doctor who is faced with an immediate situation.

Mr. GELLER. All we are saying is that Congress at least is given the information so that it can have appropriate oversight over the activities that are involved.

I agree with you that it does not affect at all what happens in the individual case. But it certainly is a check on abuse of this by the executive agency involved. Congress is told of it and is given an annual tabulation of it.

Mr. WEISS. Let me go into an area very briefly that is not national security. It is hypothetical.

Suppose you have a civilian employee of the Federal Government on a Federal facility which is subject to Federal laws. That civilian employee is driving a vehicle and gets into a very severe accident. Other people are killed in the course of the accident. The civilian is taken to a hospital because he himself is seriously injured. He is given all kinds of tests. On the basis of those tests there is reason to believe that that civilian may in fact have been under the influence of drugs or alcohol.

In that instance, what would be the right of the Federal Government to get the records of that individual civilian employee of the Federal Government without his permission?

Mr. LIBASSI. If the civilian were taken to a Federal hospital, then the provisions relating to the Federal facilities would apply.

Let me consult, if I may, on this question.

I am trying to be sure that we give a precise answer to it because the question, as I understand it, could involve private litigation of parties involving whether or not the individual was negligent.

But your question is, would the Federal Government—

Mr. WEISS. I am talking about prosecution, really, for a violation of a Federal criminal statute.

If in fact that is a complex question to give an answer to off the top of your head, I would be satisfied, Mr. Chairman, if the response were submitted in writing.

Mr. LIBASSI. I would appreciate that because I would like to be careful in answering it that we give you the exact answer. Then, if you are not satisfied with the result, you can change the legislation. I could rather not mislead.

Mr. WEISS. Right. You might want to, incidentally, build in some of the variations of that question and try to respond to it in the totality. I think it raises a number of questions surrounding this whole issue as to what in fact are the rights of the Government vis-a-vis the rights of the individual. That is really what I am trying to pose to you.

Mr. LIBASSI. You are most concerned about the rights of access to a private physician's medical record by the Federal Government?

Mr. WEISS. Right.

And that private citizen may or may not be a Federal employee.

Mr. LIBASSI. But the record is held by a Federal hospital?

Mr. WEISS. By a Federal in one instance and by a non-Federal—suppose it was a private hospital that he was taken to.

Mr. LIBASSI. But the question is, what right would the Federal Government have access to that record—

Mr. WEISS. That is right.

Mr. LIBASSI [continuing]. Whether held by a Federal hospital or a non-Federal hospital?

Mr. WEISS. Right.

Mr. KINDNESS. Will the gentleman yield?

Mr. WEISS. Of course.

Mr. KINDNESS. Could we perhaps also have the view of the Department with respect to obtain access to those records for the purpose of personnel action?

Mr. LIBASSI. Yes. All right. In terms of disciplinary action against the individual for having been under the influence of alcohol or drugs at that time.

Mr. WEISS. Right.

Mr. LIBASSI. All right.

Mr. PREYER. Without objection, we will leave the record open for your responses on this.

I might point out that in the course of the hearings we will have some other witnesses that will be going into detail in these complicated areas of alcohol information and drug information.

Mr. WEISS. Thank you, Mr. Chairman.

[The material follows:]

The supervisors of the employee, or investigative personnel may obtain records in one of two ways under the proposal:

- (1) with the consent of the individual, under sec. 202(1), or
- (2) through a summons, subpoena, or formal written request, under sec. 202(10).

The latter procedure requires notice to the individual, and an opportunity to challenge the need for the information, under requirements in sections 203 through 206. The formal written request procedure may not be used unless no administrative summons or subpoena authority appears reasonably available to the authority that wants the records. The notice to the individual may be delayed by court order (sec. 208) if there is reason to believe that notice will result in endangering life or safety, flight from prosecution, destruction of or tampering with evidence, intimidation of potential witnesses, or otherwise seriously jeopardizing or unduly delaying a trial, investigation, or official proceeding.

In the example given, the exceptions to notice would not normally apply, and so the investigative authorities would be obliged to give notice and provide the employee an opportunity to challenge the need for the record. The answer would be the same in the case of a non-Federal hospital.

If the driver were a soldier, the record could be obtained without consent, and without the notice procedures, by military authorities, under sec. 202(16).

The information could also be turned over to military claims authorities who would seek to recover the costs of the soldier's care, if there is a third-party responsible for his injuries, under the Federal Medical Care Recovery Act (42 USC 2651-53) (sec. 202(20) of bill).

Mr. WEISS. Just as a sidelight to that kind of question, Why is there the exception built into the legislation which in essence allows uniformed services to have access to medical records of individuals under their control?

Mr. LIBASSI. The Veterans' Administration and the Department of Defense felt that, in the normal course of their operations, they are constantly passing medical records back and forth for purposes of treatment, benefits, compensation, family benefits, et cetera. It would be an extreme burden to be constantly checking back with the veteran or checking back with the serviceman for consent to the continuous disclosure of these records with the Federal establishment.

Mr. WEISS. Thank you.

Thank you, Mr. Chairman.

Mr. PREYER. Thank you.

Mr. Erlenborn?

Mr. ERLENBORN. Thank you, Mr. Chairman.

Mr. Libassi, you have heard some of the questions I asked Mr. Geller. You probably anticipated I will ask some of the same of you.

Let me first ask about this area of defining exactly who is the recipient of Federal funds. Let me give you an example to tell you why I have concerns in this area. A few years ago, when I was in the State legislature in Illinois, the director of the department of conservation was indicted for violating the Hatch Act. He was appointed by the Governor. He was paid out of the State treasury. But funds from the sale of duck stamps and so forth went into the department of conservation, were used by the department of conservation.

So, the U.S. attorney came to the conclusion that he was a Federal employee under the Hatch Act and indicted him because he was engaged in political activities.

That is sort of a background. Plus, your Department's experience with title IX telling Brigham Young that they could not have rules to separate boys and girls in the off-campus boarding houses and so forth.

Who is and is not the recipient of Federal funds under this act?

Mr. LIBASSI. Let me, if I may, enlarge on your question and then try to answer it as comprehensively as I can. I want to be sure that I have made clear to the committee that we are proposing in this bill that inpatient facilities would be covered by title I of this bill whether or not they received Federal funds. So, all hospitals and nursing homes would be subject to the provisions of title I.

They would have to make records available. They would have to allow patients to correct them, et cetera.

So, with respect to title I of the bill, all inpatient facilities would be covered whether or not they received Federal funds.

With respect to outpatient facilities—that would be clinics, for instance—those clinics would be covered if they received Federal funds and the Secretary by regulation brings them within the provisions of the law.

The bill would limit the exact kinds of Federal funds that would bring an outpatient facility under the law. For instance, if a clinic received maternal and child health programs funds or community

mental health center funds, it could then be brought under title I by the regulations of the Secretary. We would list in the regulations those particular Federal programs that would bring an outpatient clinic under title I.

We do not in that area include the medicaid program. So, if a health clinic receives only medicaid funds, they could not be brought within this law.

To try to answer your question specifically——

Mr. ERLBORN. How about family planning funds?

Mr. LIBASSI. Family planning funds——

Mr. ERLBORN. They are included?

Mr. LIBASSI. Under the Public Health Service Act——

Mr. ERLBORN. How about the doctor who may be engaged through the local clinic to provide those services?

Mr. LIBASSI. If the doctor provides those services at the clinic and the record is at the clinic, the records held there would be subject to the act. But the doctor does not, by virtue of providing those services at a clinic, bring his entire private practice and his own office——

Mr. ERLBORN. What if he keeps the records in his own office?

Mr. LIBASSI. I would want to think about that one.

Let me say, with respect to private physician, the intent of the administration is not to cover the private physician——

Mr. ERLBORN. I understand. I have heard that before.

What I am trying to find out is, how can this be interpreted sometime down the road?

Mr. LIBASSI. Well, the regulations that the Secretary would issue—and here again the committee may want to strengthen the legislation in order to make sure that there is no question about how the regulations would be written—would identify the types of outpatient facilities that would be brought within the act.

In the drafting of those regulations the Secretary could make it explicit that private physicians would not be covered even though they may have a record in their possession which related to these programs.

Mr. ERLBORN. You do not happen to, in this legislation, propose that the regulations be submitted to Congress and we have a one-House veto?

Mr. LIBASSI. No, we do not.

Mr. ERLBORN. I didn't think so.

Let me get into another area.

Do I understand correctly from your testimony that you rely principally on private enforcement? In other words, if an individual feels that he has been aggrieved under this law, he has the right at his own expense to go into court to enforce the law?

Mr. LIBASSI. Yes, sir.

Mr. ERLBORN. The only other enforcement is if there are massive gross violations, the atomic weapon, so to speak, of enforcement, the cutoff of all Federal funds to the institution, may be utilized?

Mr. LIBASSI. That is correct. Yes, sir.

Mr. ERLBORN. That would be rather like what is going on in North Carolina today, I guess. I think that is your department

again starting the process of cutting off Federal funds to higher education in North Carolina?

Mr. LIBASSI. It is similar.

Mr. ERLBORN. Similar.

Some people wonder who gets hurt the most when those Federal funds get cut off: the students who are supposed to be the recipients—maybe, in the case of this act, the people in need of health care who don't get the health care because the funds are not forthcoming.

Where do the private citizens get the funding to enforce this for their own benefit? It is strictly at their own expense?

Mr. LIBASSI. It would be at their own expense, but the attorney's fees would also be available if they were successful in their litigation. But they would—

Mr. ERLBORN. Within the judgment of the court? Or is it spelled out that the court must award?

Mr. LIBASSI. It is "may."

Mr. ERLBORN. Well, that might be an incentive to some of those attorneys who feel they may get compensated that way.

As to law enforcement, title II applies to State law enforcement agencies as well as the Federal?

Mr. LIBASSI. Yes, sir.

Mr. ERLBORN. And it certainly would apply to private individuals and institutions as to their right to get records?

Mr. LIBASSI. No. Title II is a limitation on Government and only on Government agencies.

Mr. ERLBORN. I see.

Title I would prohibit the individual not a Government agency from getting access?

Mr. LIBASSI. That is right.

Title I provides that a facility would not and should not release information to a private citizen unless they have complied with the requirements of the act. So, it is a limitation on when a facility may disclose information to a Government agency or a private individual requesting it.

Mr. ERLBORN. Do I understand, then, that title I protects the individual from invasion by the general public, some private individual? Title II protects the individual from invasion either by going to the doctor's records or the facility?

Mr. LIBASSI. That is correct. Title II—

Mr. ERLBORN. There is no protection then on the individual physician's records except against the Government agency intervention in this act.

Mr. LIBASSI. In this act. That is correct—

Mr. ERLBORN. You still have your general rules that the physician must follow as a professional.

Mr. LIBASSI. Let me say that the physician under this act is free to deny disclosure of his records. No new burden is placed on the physician to disclose.

If a Government agent wishes to secure a record held by a physician, the Government must comply with title II's procedures. It still does not place on the physician an obligation to disclose if the physician chooses not to. That would be subject to other laws.

Mr. ERLBORN. Let me pose to you what is not a fanciful set of circumstances but a reality you probably are familiar with in the Chicago area, and I am sure this may have happened elsewhere.

Neither State nor Federal law enforcement officials, including HEW, seem to be doing the kind of thorough job of investigating the expenditures of medicare and medicaid funds. A private organization known as the Better Government Association in association with the Chicago Tribune, if I recall correctly, engaged in a rather extensive investigation of local clinics, private physicians' offices, other health care providers and found widespread abuse.

For instance, they would find that a particular physician or clinic was prescribing birth control pills to every man, woman, and child regardless of age who came into the facility or prescribing eyeglasses or tests to be performed by a laboratory.

When that was publicized through the newspaper, that did generate a good deal of law enforcement activity. I think it was very healthy, very healthy, because we had the BGA and the newspaper looking over the shoulder, so to speak, of HEW and the State of Illinois.

Would this act as proposed prohibit that kind of activity by the newspaper and the BGA since they were looking into individual's records?

Mr. LIBASSI. I believe that they would not have access to information which identified the individual.

I would like to be absolutely sure about that and try to answer that question, if I may, for the record. But my first impression of the statute is that they would not have access to identifiable information.

Mr. ERLBORN. So, really, the act does not condition access on the purpose of the person who is seeking access but is going to be a general prohibition. And we will find, at least in this area, that law enforcement agents acting properly under this act will be the only ones who will be able to get the kind of information as to whether or not the laws are being enforced.

We are not going to have the oversight of these citizens groups or newspapers to provide the kind of very necessary brake on irresponsible or lack of action by Government law enforcement agencies.

Mr. LIBASSI. Yes, that is correct. If I am in error in my conclusion, I will certainly advise the committee. But that is correct. The private groups and organizations would not be empowered by this act, would not be authorized to have access to private medical records for purposes of assuring compliance with fiscal integrity of rules for health care programs. That is correct.

[Additional information follows:]

The bill is intended to permit access to individually identifiable records for proper audit purposes, but to prevent indiscriminate and inappropriate access to records.

In the case given, it is arguable that a hospital would be free to open its files to a private group if that group were conducting a true audit or evaluation, and if it fulfilled the conditions set out in the bill for such non-governmental audits. (sec. 105(b)(7).) The inquiry would have to be a true audit or evaluation, conducted by people professionally qualified to do this work, and conducted using generally recognized systematic audit and evaluation techniques. The personnel doing the audit or evaluation would have to give assurances that individually identifiable information would be safeguarded against improper disclosure, and would be disclosed only under the limited circumstances permitted in the bill, i.e., for the purposes of the audit or evaluation, in health or safety emergencies, or pursuant to compulsory legal process. A record of the access would have to be maintained.

The hospital would be permitted to disclose individually identifiable information only to the extent needed to accomplish the audit or evaluation.

Thus, to the extent that the activity conducted by a private watchdog group meets the same standards as would be met by any other private audit, the activity inquired about could be permitted under the bill.

Our bill would of course not require any disclosure for private audit purposes, but simply permit it.

Mr. ERLNBORN. Thank you, Mr. Chairman.

Mr. WEISS. Will the gentlemen yield?

Mr. ERLNBORN. Yes.

Mr. WEISS. Would you also be able to tell us—and perhaps for the record—how this legislation ties in with the provisions of, I believe, H.R. 3, which was adopted in 1977, which deals specifically with medicare and medicaid fraud and abuse and enforcement at the State level with some Federal funding assistance.

Mr. LIBASSI. I would be pleased to submit a memo on the relationship between the administration's proposal and H.R. 3. I would like an opportunity to work that out with the inspector general of the Department.

[The material follows:]

We have been careful in drafting our proposal to ensure that State and Federal auditors would be able to gain access to individual medical records, without patient consent, for the purpose of protecting the fiscal integrity of these programs. Section 105(b)(6) of our bill would permit access to patient records --

(6) to persons presenting appropriate evidence of their official status who state in writing that they need the information --

(A) for a government public health investigation, for a government investigation of activities of the facility, or for a Federal, State, or local government audit or evaluation purpose, or

(B) to carry out a program under title V, part B of title XI, title XVIII, or title XIX of the Social Security Act, or other government program providing payments to, or concerned with activities of, the facility, or to conduct an investigation concerning fraud, abuse, or waste under those programs.

The only requirement on the medical care facility in connection with such access is that a record be maintained of each request for such access and that those records be made available to patients on request.

Mr. WEISS. Thank you.

Mr. KINDNESS. Will the gentleman yield?

Mr. ERLNBORN. I would be happy to.

Mr. KINDNESS. Thank you.

Going down this road just a little bit further, I can see that the institutional review boards' members might very well say in every case presented to them, no we won't release the information; you go to court and get the court to determine the question.

Has any thought been given to that aspect of it, particularly since members of the institutional review board would be subject to a civil action perhaps with some regularity?

You would either have difficulty finding people willing to serve on such boards, or their answer would automatically be no.

Is there a problem there?

Mr. LIBASSI. With respect to research projects, a facility may make the decision to disclose or not disclose on its own. Or the facility may rely on the judgment of an institutional review board. It can be either the hospital's institutional review board or it can be another institutional review board which they use.

Mr. KINDNESS. Excuse me. I have already concluded that the hospitals are going to say no in every case so that they do not have this additional liability.

Mr. LIBASSI. If the institutional review board felt that the research project was not worthy of disclosure, did not feel that it was of such a social purpose that the person's privacy should be invaded, there is no liability for the institutional review board for refusing to make the record available.

The only liability that might arise is if the institutional review board was arbitrary and capricious in allowing disclosure. Then the parent organization would be subject to suit, but not the institutional review board.

Mr. KINDNESS. So, could not we sort of foresee that, in these cases, the hospital is going to say no and the institutional review board is going to say no, and the information will not be available for the research purposes because they face the potential of a lawsuit?

Mr. LIBASSI. It is possible that some institutions may choose not to disclose on the grounds that it is a questionable practice and they wish not to get involved in it.

But, by and large, institutions are now cooperating in making information available. They would have the security of knowing that the procedures are clearly spelled out by statute. If they have complied with those procedures, they would be protected.

Actually, the individual would have the right of suit in the research situation against the research agency for misuse of its data. But, if it were a legitimate research project and the hospital complied with the requirements of the law, the hospital would not be liable. So, I think the hospital in a way has the confidence of knowing that, where a research application comes in, there is a law which sets a standard. Then they can feel free to go ahead and make disclosure. Some may choose not to.

Mr. KINDNESS. In fact, under the current drafting of the proposed legislation, I guess a civil action would not lie unless and until a

person had been convicted under section 301 of the misdemeanor section; would it?

Mr. LIBASSI. No. A private civil action could be brought even though no criminal action had been initiated.

Mr. KINDNESS. It could be brought against the medical care facility or the institutional review board or governmental agency.

Mr. LIBASSI. That is right—or the researcher, or research organization, could also be sued. If they either improperly secured the information, or redisclosed it improperly, then the research organization would be subject to suit; but not the hospital for originally having made it available to the researcher.

Mr. KINDNESS. The research agency would only be subject to civil action for the commission of acts which constitute a crime under section 301, that is obtaining the information under false pretenses.

Mr. LIBASSI. I would hope they would be subject to a civil action for more than that.

Mr. KINDNESS. Or violation by a researcher of any provision of section 105(b)(5). I see.

Mr. LIBASSI. That's it.

Mr. KINDNESS. Thank you.

Thank you, Mr. Chairman.

Mr. PREYER. Thank you.

We have one other witness today. There are some further questions which we will want to put to you. If we do not get the information on these other questions in the record later on, we may ask you to submit answers in writing to these. I am thinking in terms of the costs that will be incurred as a result of medical records legislation, on whom you think the costs will fall, whether it is on the record users or whether it is on the recordkeepers. I believe Mr. Geller mentioned that startup costs are the only thing you anticipate. So, we may want to know a little further about that. Also, there is the question which was discussed with him a little earlier about the necessity of new types of recordkeeping controls on the part of hospitals.

We will be going into those later on, I think. It may be we will want to call you back to get further information on that.

I do have one final question I would like to ask Mr. Geller.

This subcommittee has jurisdiction over the U.S. Postal Service, the FCC, Department of Justice, and Government information policy. There is a current dispute going on between the Postal Service and the FCC about jurisdiction over and the development of electronic mail systems.

Could you briefly tell us whether the administration is developing a position in this area and whether it involves a decision that this subcommittee and Congress should ultimately make?

Mr. GELLER. Yes, sir. There is a dispute in the area, as you mentioned. The administration is developing its position to what is called a Presidential response memorandum. All the agencies that are involved, including the U.S. Postal Service, have come together to thrash out the issues and to present them to the President for a decision.

We believe very strongly that that decision is one for this Congress. It should not be made by the USPS or by the Postal Rate

Commission. They can only look at it from the viewpoint of the Postal Service.

It should not be made by the FCC. They can only make it from the point of view of the private sector. It deals with telecommunications only in the private sector.

The only entity that can look at it overall and look at this issue from what is best for the Nation taking into account both the Postal Service and the overall telecommunications including the private sector is the Congress.

Therefore, when we have worked out the administration's position, we believe it ought to be presented to the Congress. It is the Congress which should decide this issue. This would serve the Postal Service well also. They would then know how to plan. The private sector would be served by it; it would know what the ground rules are.

But it is for the Congress, we think, to lay down the ground rules here.

Mr. PREYER. Thank you very much, Mr. Geller.

I want to thank all of you for the obvious thought and hard work that has gone into your recommendations. We will certainly look forward to working with you in the future on this. I hope we can develop some very helpful legislation in this area.

Mr. GELLER. Thank you.

Mr. LIBASSI. We look forward to it.

Mr. PREYER. We will excuse you at this time.

[Mr. Libassi's prepared statement follows:]

FOR RELEASE UPON DELIVERY



DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

STATEMENT

BY

F. PETER LIBASSI
GENERAL COUNSEL

BEFORE THE

SUBCOMMITTEE ON GOVERNMENT INFORMATION
AND INDIVIDUAL RIGHTS
COMMITTEE ON GOVERNMENT OPERATIONS
UNITED STATES HOUSE OF REPRESENTATIVES

WEDNESDAY, APRIL 4, 1979

I am happy to be here to discuss with the Subcommittee proposals for legislation to protect the confidentiality of medical records. In addition to your own bill, H.R. 2979, you now have before you the Administration proposal in this area. My statement will highlight some key features of our proposal. We look forward to working with you closely on these proposals.

The bill is based in large part on the recommendations of the Privacy Protection Study Commission, established by Congress to study information systems, in the health-care and other areas. In its charge to the Commission, the Congress directed it to advise on steps necessary "to protect the privacy of individuals while meeting the legitimate needs of government and society for information" (sec. 5(b), P.L. 95-579).

The concern of the Congress that motivated the establishment of the Commission was based on the dramatic changes in record-keeping and its relationship to privacy that have occurred in recent years. The Commission's inquiry noted these changes, and their consequences, with special force in the case of health care records.

The information in medical records is of special sensitivity, and requires special protection against disclosure. To get effective medical care a person must reveal sensitive, often intimate, personal matters, so that physicians and other health professionals have valid information on which to make diagnostic and therapeutic decisions. As

we increase our awareness of the effects of our environment and personal lifestyle choices on health, health records may contain even more private information such as food and alcohol intake, sexual activity, recreational pursuits, travel and past residences. Developments in genetics have also encouraged the collection of information on the health status and environmental history of relatives.

Medical developments that have increased the volume, complexity, and sensitivity of the record have been paralleled by social and technological developments that weaken the traditional protections for the confidentiality of the record. Physicians and other health professionals have always had and observed ethical prescriptions about their patients' confidences; and certain State legal protections, like physician-patient privilege and other statutory barriers to disclosure, have also been an element of the protection.

In the past, the principal controls were informal ones; the health care system was such that the traditional ethical and legal protections were effective. Today, these controls are not sufficient. Most of our health care is not obtained from physicians. Large, impersonal institutions provide care. The record is needed by many persons and institutions far from the physical, administrative, and ethical controls of physicians. . Third-party payers, researchers, law-enforcement officials and others need medical record information in connection with transactions involving the patient, as well as for uses not explicitly involving the patient. In addition, more information is maintained by computerized systems; this

presents special problems of security and unauthorized disclosure and use. It also encourages the centralization of records, with the benefits and hazards inherent in such centralization.

Our proposal offers a Federal baseline of essential protections that all our citizens ought to have with respect to their records. Patients go from State to State, receiving care in many places. Information is transferred, with or without the patient's consent, from one State to another. The maintenance, use, and disclosure of medical information has become a national business. It requires the comprehensive, systematic approach that can be provided by Federal legislation.

Brief Description of Our Proposal

Our bill has two basic purposes: (1) to establish fair information practices for the holders of medical records, and (2) to place limits on government access to private medical information. Title I of the bill addresses the first purpose by establishing requirements for patient access to and correction of medical records and by restricting the types of disclosures that may be made of a patient's medical record without his approval. This title would apply to all inpatient facilities and the Secretary could by regulation impose the rules on outpatient facilities receiving Federal grant funds. Title II of the bill would impose obligations on government authorities, both Federal and State, in obtaining information about patients from any health care providers, whether or not those providers are subject to the obligations relating to patient access, disclosure, and consent. Government agencies could

obtain information only in circumstances, and under conditions, set out in the bill.

Health care providers would have no obligations under title II. The government agency would have to fulfil the requirements in seeking information from any health care provider, including physicians in private practice. With this background I will describe the provisions of the bill in more detail.

Title I

Title I prescribes how medical care facilities must treat written information which they maintain about their patients. It would cover all hospitals and nursing homes - in short, inpatient facilities. It would also cover, to the extent provided by the Secretary of HEW in regulations, outpatient facilities which receive grant funds under the Public Health Service Act, the Community Mental Health Centers Act, the Maternal and Child Health program under title V of the Social Security Act, the Comprehensive Alcoholism Prevention, Treatment and Rehabilitation Act of 1970, or the Drug Abuse Office and Treatment Act of 1972.

This title would cover also Federal medical care institutions, and the Privacy Act would be amended so that the disclosure and patient access provisions of this Act would replace those of the Privacy Act for Federal hospitals. Federal institutions would still have to comply with such Privacy Act requirements as the publication of a system notice; and the Act's criminal penalties would apply as they have in the past. The

result would be that the rules for disclosure and for patient access would be the same for all hospitals, simplifying all dealing with hospitals. Hospitals operated by State and local governments which do not receive Federal funds would not be covered.

Patient Access

Under the bill, patients would be able to see their records, or designate others to do so for them, and obtain copies of materials in the records. An institution would have twenty days to provide this access, affording it flexibility, for example, to grant access only on certain days of the week, or to give a physician who has contributed to the record a chance to review it.

There is a provision for the facility to channel the record through a third-party, of the individual's choice, where the facility determines that direct access would be harmful to the patient or to another person.

In general we support the view of the Commission, and many observers of the health care scene, that patients should be able to see their own records. Such a right is essential for an individual to make intelligent choices about whether to authorize certain disclosures. It is already established by statute in ten States in approximately the form we propose, and fifteen more States provide access in limited ways, or with restrictions. At the same time, there may be instances in which prudent medical judgment concludes that direct access by the patient would be harmful, and in such cases the draft bill provides for channeling the record through a third-party.

Correction

A patient would be permitted under the bill to seek correction of a record. Under the proposal, if the facility declines to change the record, the patient may file a concise statement setting forth the patient's view. The hospital would have ninety days to make a decision about correction, thus permitting consultation, if the hospital wishes, with those who have made entries in the record.

The patient's right of access to and correction of information does not extend to materials assembled in reasonable anticipation of civil litigation. This provision is similar to one in the Privacy Act, and is designed to keep the patient access provision from serving as a covert discovery mechanism.

Disclosure Limitations and Exceptions

The expectation of confidentiality that the patient is entitled to is established by sections 104 and 105 of the bill. Disclosure of information about a patient is prohibited unless the patient consents or unless the disclosure falls within one of the authorized disclosures spelled out in sec. 105 and the institution complies with the conditions for such disclosures.

The disclosures permitted without consent fall into four general categories:

- (1) Disclosure in the normal operation of the institution, or needed for the patients' care, or for other health or safety purposes.

- (2) Disclosures in which the specific identity of the patient may be needed, but is incidental to the use, and in which the individual will not normally be affected. Research, audit, and certain uses for payment programs fall into this category.
- (3) Disclosures which may affect the individual, but where it would thwart the purpose of the disclosure to seek consent. Some of these disclosures have specific procedural safeguards.
- (4) Disclosures within the Federal Government, where consent requirements would thwart important government objectives (as in the case of members of the uniformed services in Federal hospitals), or are already covered under other statutes (as in the case of Veterans Administration use of health records to determine claims) and obtaining consent would be merely formalistic in any case.

We have given a great deal of thought to the framing of the non-consent disclosures and the conditions surrounding them.

The Commission noted the sharp clash between society's interest in protecting medical confidentiality, and its interest in the wide variety of other important functions for which medical records are needed. The clash is not easy to resolve, or even mitigate. However, the confidentiality of the medical care relationship has been seriously eroded, and needs to be restored.

The solution, in the Commission's view, is not simply to block third-party access. Individual uses have to be evaluated, and societal judgments made about their appropriateness. The bill is an attempt to do that.

We have observations on some of these particular uses.

Patients' Relatives

We have included an exception for disclosures to next of kin, and others close to the patient, consistent with accepted medical practice, to accommodate emergency situations where, for example, a close relative or friend inquires about an unconscious patient and it is appropriate to reveal details of the patient's condition. More specificity about such disclosures is not workable, and we would prefer to rely on medical personnel in the operational situation to make the choices and judgments necessary to maintain confidentiality and at the same time respect the emotional needs of the patient and those close to the patient.

Research Disclosures

The disclosures permitted for research and statistical purposes would be subject to conditions set out in the bill. Once a researcher obtains the information, the conditions governing its use parallel those in the separate research confidentiality bill that is part of the Administration's privacy initiative.

Much health research depends on access to identifiable records in situations where patient consent cannot be feasibly obtained, or where to

permit patients to grant or withhold consent would bias the results. Examination of a medical record, followed by efforts to locate the individual or other records about him, in order to determine his health status, is a principal tool in studying the course of a disease in the population. This is done, for example, to study the course of illness over a long period of time, particularly in conditions which are not of common occurrence in the population at a single point in time, but which take a heavy toll over a long period, e.g., cancer. In all of these activities, access to medical records is a necessary first step in identifying patients so that they can be contacted, and, if they consent, be interviewed and studied, or so that subsequent records, such as death records, can be examined. This approach is vital in epidemiologic studies, in clinical studies of the natural history and prognosis of disease, in the evaluation of new modalities for the early detection and treatment of disease and in identifying factors associated with increased risk of disease.

Our bill would require the facility to make certain explicit determinations before disclosing information for a research purpose. Facilities would be permitted (but not required) to rely on an Institutional Review Board (IRB) to make or review these determinations, which require scientific expertise. There is no obligation to use the IRB, but an institution which relies on one is freed from civil liability for its determination that that disclosure for research is appropriate. A disclosing institution need not use its own IRB. It may not have one, and in such cases it may want to rely on the determination of the IRB at the institution sponsoring the research.

Audit Disclosures for Health Program Purposes

Government audits, investigations, and evaluations are directed primarily toward facilities or health care practitioners, and the bill would permit disclosures for these activities. Related to this are disclosures to Federal or State authorities, and health insurance plans, for the purpose of determining the cost of care in the facility.

Among the disclosures now customary or permitted or required by law are disclosures for routine audit, other detection efforts, investigations, and civil, administrative and criminal enforcement actions. Other important areas are audits and evaluation of program performance, and of medical care. The Food and Drug Administration also needs access to records for regulatory compliance and public health protection purposes. There is a serious problem of fraud, abuse, and waste in publicly funded medical programs. The control of such fraud and abuse requires a commitment to detect, investigate, and prosecute (civilly, administratively, and criminally) those who engage in fraud or abuse. This, in turn, requires that auditors, investigators, and prosecutors be given access to medical records.

In such disclosures to non-governmental institutions or agencies the facility must, under sec. 104, assure that only as much information is disclosed as is needed to accomplish the purpose of the disclosure. In the case of official government audits and inquiries, the government agency is responsible for this limitation, since it would thwart the purpose of such an audit or inquiry to require or even permit the facility to control, limit, or screen the records necessary to the inquiry,

when the facility is typically the target or potential target of the investigation.

Mandatory Reporting

The draft bill would permit facilities to comply with requirements for reports to health departments of conditions of public health interest, and requirements for reports to law enforcement authorities. In the latter instance, the facility could make whatever report is required by law; if a law enforcement authority then wanted more information from the record it would be required to follow the requirements in title II.

Other Government Disclosures

The Secret Service and Federal intelligence authorities could be provided with information for the specialized needs of those authorities, pursuant to formal request.

Internal Federal Uses

There are some exceptions to accommodate existing disclosures within the Federal Government. Uniformed services and penal and correctional authorities may have access to material relating to individuals under their control. In the uniformed services this exception does not extend to dependents; their records can only be disclosed pursuant to an authorization or one of the other exceptions. The Veterans Administration may use information from its medical care facilities for claims purposes, and may also obtain information from the uniformed services to assist in determining benefits.

Disclosure may be made to the Department of Justice, as an agent of a facility, in litigation relating to medical care, in the same way a non-Federal facility may provide the record to its attorneys.

Disclosure Pursuant to Process

Information may be disclosed without any notice or other procedure pursuant to compulsory process in litigation or an equivalent directive in an administrative action when a Government agency and an individual are parties.

Information may be disclosed in private litigation in accordance with existing law.

For other disclosures to Government authorities, pursuant to administrative summons or subpoena, search warrant, judicial subpoena, or formal written request, the health care facility must receive a certification in writing that the Government authority has complied with the applicable requirements of title II of the Act.

Notification of Patients

Facilities would have to prepare a notice to let their patients know what disclosures may be made of information about them without their authorization. It must provide the notice to patients when first providing care to them, and also make the notice available upon request. This is an important feature of the protection, largely because it educates patients with respect to the use of information and permits them to take steps to affect uses which they may disapprove of.

Authorization by Patients

The bill establishes standards for the content of patient authorization for disclosure. They must be in writing, signed, and dated. The facility that is to do the disclosing and the intended recipient of the record must be named specifically or by generic category. We have allowed generic categorizations to accommodate such situations as application for disability benefits, where the applicant may not remember all facilities in which he was treated. Likewise, a facility may wish to disclose some elements of a patient's record to a series of potential third-party payors; the patient may not know exactly what insurance plan or government program covers his care, but can authorize the facility to disclose a limited amount of information to identify such a funding source.

We have not included the requirement, recommended by the Commission, that the authorization include the purpose for the disclosure. The scheme of the Administration's Privacy Initiative does not envision that recipients of information will be legally bound by conditions in an authorization. At the same time, patients may not wish their health care facilities to know why they are asking that information be disclosed. Since there is a potential hazard to privacy in requiring this detail, and there is no sanction for improper use even if a purpose is stated, we concluded not to require a stated purpose.

Title II

Let me move on to the requirements of title II of the bill. As I indicated earlier, this title spells out the circumstances under which

State and Federal authorities may obtain information from health records held by any health care provider, whether or not the provider is required to observe the requirements in title I. Title II is meant to protect the records of individuals served by anyone who provides health services, including, but not limited to physicians, dentists, nurses, optometrists, physical therapists, occupational therapists, psychiatric social workers, clinical dietitians and clinical psychologists, as well as institutions or agencies providing any health service. This title does not impose new direct obligations for the confidentiality of patient records on these providers; its obligations are on Government authorities who seek records.

Government authorities may generally obtain information under the same circumstances under which health care facilities may disclose information under the provisions of title I. Thus, information for research, audit, evaluation, medical emergencies, care of the patient, payment of claims and similar uses may be sought and received by government authorities to the extent necessary to accomplish the purpose for which the disclosure is to be made. The conditions surrounding such access are similar to those governing disclosure in title I. For example, a government agency receiving information for research must give all the assurances and is bound by the same restrictions on re-use that a private researcher would be bound by.

Attempts by government agencies to obtain information by summons, subpoena, search warrants, and formal written request, under circumstances not

otherwise permitted by the bill, would be subject to a number of procedural protections to assure that, where at all possible, the individual whose record is sought has an opportunity to be heard. If a Federal or State authority seeks medical information under an administrative summons or subpoena, a judicial subpoena, or a formal written request, and if a medical care facility in the circumstances would have no basis under the bill for disclosing the information, there would have to be reason to believe the records sought were relevant to a legitimate law enforcement inquiry. The authority would have to notify the individual in advance that it wanted medical information concerning him. The form of the notice is prescribed in the bill.

The notice would be served on the individual or mailed to his last known address. The authority would have to wait 10 days from service of the notice or 14 days from mailing, to give the individual an opportunity to challenge the summons, subpoena, or request in court.

The advance notice requirement could be set aside by court order if there were reason to believe that notice would result in danger to anyone's physical safety, flight from prosecution, destruction of evidence, intimidation of witnesses, or would otherwise seriously jeopardize an investigation or proceeding. Delays of up to 90 days could be granted, and further delays could be granted on the same showing of necessity. After the delay expired the individual would have to be notified that the information had been obtained, and of the basis for the delay.

Challenge Procedures

An individual who was notified of a Federal or State agency's intent to obtain medical information concerning him could file a motion to prevent the disclosure. The individual would file a sworn statement that he was the person about whom information was sought and would state his reasons for believing that the information was not relevant to the investigation, or that the Government authority had not substantially complied with the requirements under the draft bill. If the court found that there was a reasonable belief that the information was relevant, and that there had been substantial compliance with the draft bill, the information could be disclosed. Otherwise it could not be disclosed.

I want to make clear that these notice and challenge provisions would not apply in those cases where government authorities could obtain access to records without formal process. Thus, an agency conducting a public health investigation, a financial audit, or a program or research audit or investigation could obtain information under the specific provisions in the bill permitting access for these purposes. In such a case, even if the provider refuses the request for access and forces the government agency to use a subpoena or warrant, the agency would not be obliged to provide the notice to the individual required by the provisions governing subpoenas and warrants, so long as the purpose of the access is covered by one of the exceptions provided for government access under title II.

Agencies which have such authority are normally directing their inquiry at the facility, or are gathering information for public health purposes,

as in the case of the Food and Drug Administration and the National Institute of Occupational Safety and Health. To require notice and an opportunity for challenge in such cases would be to require a prohibitive administrative task, and would serve no purpose of the individuals, who are not being investigated.

Emergency Situations

In some situations, advance notice would cause serious harm, and the delay to get a court order would be intolerable. Thus, the bill allows Federal or State authorities to obtain medical information upon request without advanced notice if the information is immediately needed to prevent imminent danger of serious property damage, or of flight to avoid prosecution. The individual would be notified of such access as soon as practicable, but notice could be delayed on the same grounds and under the same procedure applicable to delay of advance notice for summons, subpoena, or formal request. The Government authority would also have to file with the appropriate court within five days a signed, sworn statement setting forth the grounds for the emergency access.

This provision does not apply to emergency disclosures for personal health and safety. They are allowed by another provision of the bill, and must be noted in the patient's records.

Search Warrants

Federal or State authorities that obtain medical information by means of search warrants would have to notify the individual within 90 days, unless a court granted a delay on the same grounds and under the same

procedure applicable to delay of advance notice, or unless a medical care facility in the circumstances would have another basis under the draft bill for disclosing the information.

Grand Jury Subpoenas

Medical information obtained pursuant to a grand jury subpoena would have to be presented to the grand jury, and destroyed or returned to the health care provider if not used for grand jury or related purposes.

Further Disclosure

There are restrictions on further disclosure of information obtained under a summons, subpoena, search warrant, or formal written request, or in emergency situations. A Government authority that received information this way could transfer the information to another government authority only if it received a certification that there was reason to believe the information was relevant to a legitimate law enforcement inquiry within the jurisdiction of the receiving authority. The transferring authority would have to notify the individual that the transfer was made. The notice could be delayed if the transferring agency had already obtained a court order for such delay, or if the receiving authority obtained such an order, on the same ground and under the same procedure applicable to delay of advance notice.

Other Aspects of the Bill

Let me discuss now the penalties for violations of the provisions of the proposed statute.

Individuals harmed by a violation by a facility, a government agency, or a researcher of their obligations under any portion of the bill, or by a person who obtained information under false pretenses, could bring suit in a U.S. District Court or other court of competent jurisdiction, and could obtain actual damages, up to \$10,000 in general damages, reasonable attorney's fees, as well as equitable and declaratory relief. In the case of State agencies, States which waived sovereign immunity could be sued; in States which did not, suit could be brought against individual State officials.

In addition to this principal enforcement mechanism of private civil suits, Federal funds could be denied to facilities which failed to provide assurances of substantial compliance with their obligations under title I. This would include the revocation of certification under Medicare and Medicaid, and the cut-off of funds under direct grant programs.

There would be criminal penalties for requesting or obtaining information under false pretenses from any health care provider.

Other Safeguards and Rights

Federal authorities which obtain information for certain emergency purposes, or for intelligence or Secret Service protective functions, must compile an annual tabulation of these occasions.

Federal authorities would be required to pay health care providers to search for and copy records obtained under a summons, subpoena, or search warrant, or for certain emergency situations, or for intelligence or protective functions, or pursuant to patient authorization.

Childrens Records

Our proposal does not deal directly with the difficult issue of childrens records. The bill would authorize the Secretary to prescribe by regulation the situations in which it would be in the interest of an individual under 18 years of age to exercise his own rights. We have no definitive answer now on how this might be handled. Ideally, parents will be involved in their children's health care, but we are also strongly committed to the goal of permitting young people to have responsibility for their own care, especially when a requirement for parental involvement would cause them to delay or omit treatment. Virtually all States permit minors to consent to their own treatment for certain conditions. The handling of records should be such that it does not thwart the purposes of those State statutes. Thus, it may be appropriate to have a rule that would permit adolescents to control their own records. However, it is difficult to write a rule applicable in all cases. Young people differ greatly in maturity, judgment, and their ability to manage their own affairs. We have begun to look at possible approaches.

One approach would be to permit parents to exercise rights on behalf of their children except when the child has consented on his own to treatment, as allowed by State law. This presents certain practical problems, since a single record is hard to divide on the basis of who consented to the treatment. We look forward to hearing the views of professionals knowledgeable about this, and to discussing it further.

Relationship to Other Laws

Let me discuss briefly the relationship of the proposed statute to existing statutes governing confidentiality, patient access to records, and the availability of records for disclosure. All existing statutes, Federal and State, which are not inconsistent with the proposal would remain in force. Thus, if State laws forbid disclosures which our proposal would permit, those disclosures could not be made. The statutes governing the confidentiality of drug and alcohol abuse patient information (sec. 408 of the Drug Abuse Office and Treatment Act of 1972, and sec. 333 of the Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and Rehabilitation Act) provide more stringent protections for this especially sensitive class of records than our proposal does, and those more stringent protections would have to be observed. On the other hand, the drug and alcohol confidentiality statutes do not provide patients with a right of access to their own records; such a right would be granted in accordance with the proposal we are presenting.

There is another point that should be made with respect to the disclosures permitted by the bill we recommend. No disclosures to third parties are required by it. The facility would not be obliged by this bill to make any of the disclosures permitted by Sec. 105(b). There are other statutes which require disclosures, and if this bill permits those disclosures, they must be made, pursuant to those other statutes. For example, it is a condition of Medicare and Medicaid participation that the facility allow its records be reviewed for cost determinations, and the Comptroller General and the Inspector General of HEW have authority generally to

inspect records of facilities receiving Federal funds. Likewise, State laws require that facilities be audited, and that certain facts, like communicable diseases, be reported to health authorities. Certain public health authorities can compel disclosure of information by formal process. Our proposal is designed so as not to interfere with these disclosures on which there have been legislative decisions to require disclosure, but it does not of itself require any such disclosure.

Concluding Remarks

We have designed this proposal with care to avoid unnecessary record-keeping, notifications, and other paperwork. Likewise, we have avoided prescribing management mechanisms, such as appeal procedures within institutions. Medical care facilities can to the greatest extent possible build on their existing procedures; the bill we suggest would offer a uniform, national set of substantive rules on patient access, and disclosure standards, with a minimum of additional effort.

The protection of the privacy of individuals with respect to medical information cannot depend solely on one statute, or even a set of statutes. Careful management, a strong ethical sense on the part of practitioners, thoughtful policy consideration when establishing data systems, are all necessary, and they cannot effectively be compelled by law. The present legislative proposal is an attempt to provide the essential legislative base to support those efforts.

Mr. PREYER. Our last witness today is Dr. Alfred M. Freedman, who is chairman of the National Commission on Confidentiality of Health Records. He is accompanied by Mr. Robert Belair.

We appreciate your being here today. We will admit your testimony into the record, without objection; and you may proceed in any manner you see fit, Dr. Freedman.

STATEMENT OF ALFRED M. FREEDMAN, M.D., PRESIDENT AND CHAIRMAN, NATIONAL COMMISSION ON CONFIDENTIALITY OF HEALTH RECORDS; ACCOMPANIED BY ROBERT BELAIR, COUNSEL; AND TOBY LEVIN, ASSISTANT EXECUTIVE DIRECTOR

Dr. FREEDMAN. Thank you, Mr. Chairman.

I am Alfred M. Freedman, chairman of the National Commission on Confidentiality of Health Records and a past president of the American Psychiatric Association. To my right is Mr. Robert Belair, who is counsel to the National Commission on Confidentiality of Health Records; and on my left is Ms. Toby Levin, assistant executive director of the National Commission on Confidentiality of Health Records.

I certainly feel privileged to be here this morning in my role as president. I want to congratulate the chairman and the committee on its leadership in the privacy field and for being the first committee to hold public hearings on perhaps the most critical of all privacy issues, confidentiality of health records.

Let me say something about the history of our commission. It is a federation of some 24 national organizations whose purpose is the preservation and the promotion of confidentiality of health records. This has been a concern of ours for a long time. Actually, it owes its genesis to the Watergate years, when the American Psychiatric Association, of which I was then president, was shocked into taking concrete action on behalf of patient privacy.

You remember the disgust of Senator Sam Ervin of North Carolina, when the Ellsberg-Fielding episode was brought before the Senate Watergate Committee, and those responsible for breaking into a private psychiatrist's office did not seem to know they had done anything wrong.

This mobilized us into action. Agreeing with Senator Ervin, we convened a conference in 1974 at Key Biscayne, Fla. There some 50 national medical and consumer organizations came together and on the basis of their decision, we launched a National Commission on Confidentiality of Health Records in 1976. We started with 17 national groups ranging from the American Psychiatric Association, the American Academy of Pediatrics, to the Blue Cross, and the American Hospital Association.

We have increased in numbers since that time to 24, including the National Congress of Parents and Teachers and the American Statistical Association. Our organization has established itself as a vigorous nonprofit group promoting a fair balance between the patient's right to privacy and society's legitimate needs for personal health information—a conflict, of course, that all of you recognize.

Through its informational and educational activities, including its National Clearinghouse publications and its comments on Fed-

eral and State legislative and regulatory proposals, the National Commission on Confidentiality of Health Records has sought to increase national awareness of health confidentiality problems and obligations.

In the 2½ years of our existence, we have been distressed by the continuing erosion of practitioner-patient confidentiality and the tremendous rise in the demands of third parties for health record information.

Confidentiality is the key issue. In general, access to patients' records should be with patient consent. In this regard, we favor the Privacy Protection Study Commission's patient consent standard.

However, we recognize that it is impossible in today's health world to keep health information totally within the private circle of the health care provider and the patient. Health care has entered the computer age and the increased demand by such third parties as insurers, government agencies, researchers and employers for access to personal health data has created a virtual revolution in health record keeping.

We have concerns about those disclosures made without patient consent, particularly in the area of government access for anti-fraud, third-party payment, and law enforcement reasons. We have concerns, too, in the area of private business access by insurers, employers, and others. And we also have concerns in the area of researcher access.

Unrestricted access by third parties, even for legitimate reasons, can cause serious problems for patients when medical information "gets around". It can lead to embarrassment, strained or broken relationships with family, friends and work associates, career and economic damage including loss of job or promotion, denial of insurance benefits, or refusal of admission to graduate school.

These issues have been made very clear in a number of letters that we have received at the commission office. Let me illustrate.

THIRD-PARTY PAYERS

With regard to third-party payments, one must appreciate that nearly 70 percent of health care costs, including 94.1 percent of hospital expenses and 61.2 percent of physicians' bills, involve third-party payment. So there is great interest on the part of insurance carriers in patient records for underwriting and claims processing purposes.

Patients and practitioners legitimately complain that insurers often ask for photocopied hospital records and highly detailed psychiatric reports that I personally can attest comprise more information than they really need. In addition, once information is collected by an insurance company or an investigative agency, it is widely traded within the entire industry through such groups as the Medical Information Bureau which holds information on some 11 million people.

Another issue is raised when health care is paid for through a group insurance plan, and medical data often ends up in the hands of the patient's employer. As a result—and I would like to emphasize this point particularly because it is one that is not often appreciated—many individuals will not use their psychiatric cover-

age for fear of repercussions at work. They feel it may endanger their job or their future career development. Others are mystified when applications for life, health, or disability insurance are inexplicably rejected.

Two examples from the National Commission on Confidentiality of Health Records' correspondence illustrate some of these problems. For example, in one case a woman who had applied for group insurance was notified that her coverage would be limited because she had high blood pressure. Although she immediately protested she had never had such a condition, the insurance company would not answer her letter to explain how it had obtained the false information.

In another case, a young woman wrote that she was mistakenly diagnosed as an epileptic and was denied insurance based on this mistaken diagnosis. She wanted to know how such information was obtained and how to correct it so as not to be permanently uninsurable.

Once mistaken, incomplete, or distorted information enters the insurance data system, correcting it can be very difficult. When an application is rejected, the applicant rarely knows why or how to contest the decision. Patients often write us that they conceal previous treatments for medical and emotional problems rather than subject themselves to negative assessments of their insurability.

A dramatic example of insurer abuse was related to us by a New York physician who refused to disclose information about one of his patients to an unidentified woman over the telephone. After several calls, she identified herself as an insurance investigator but still refused to say why she wanted the patient information. Harassment escalated to the point where the physician said the investigating agency "was going to open a file on me with the inference that my noncooperation will now be part of my credit record." Such practices run counter to the policies recommended by the Privacy Protection Study Commission and recently adopted by a number of insurance companies.

GOVERNMENT ACCESS

Government sources often make troubling demands for personal health information. If health care is financed through State or Federal Government funds, extremely complicated systems have usually been set up to prevent fraud and abuse and assure a reasonable standard of care in health care programing. Health and welfare officials, professional standards review organizations (PSRO's), hospital certification authorities, and fraud investigation units may all receive medical information or seek direct access to patient records. This vast store of information accumulating in government files disturbs many practitioners and patients.

In many government agencies, circulating health information through multiple and often duplicating levels of reviews seems to receive a higher priority than safeguarding confidentiality. This seems unlikely to change as the Government's role in health care and health insurance expands.

Again, we have many letters in our files about Government demand for health information, probably more than about any other issue. Some have actually come from government officials themselves requesting assistance in resolving conflicts between reviewing agencies and practitioners.

A drug abuse clinic administrator wrote us that his clinic's records were reviewed by some 10 representatives from five separate government agencies in the course of a year. He felt strongly that this made a mockery of confidentiality. He also questioned the qualifications of reviewers who lacked professional training and who giggled while examining patient records.

Another dimension of government access to medical information is the increased demand for compulsory reporting to public health authorities. A Florida community mental health center president strongly opposed a new Florida regulation requiring compulsory reporting of names, social security numbers, and addresses of all patients. After protests, the State's action was postponed to July 1979. But, to our knowledge, the matter has not been resolved.

In a similar vein, a New Jersey hospital administrator raised objections to the increasing demand by government agencies for personal and social data, usually for well-intentioned research studies, but all too often through methods which expose the lives of private citizens. He was particularly concerned when the New Jersey Department of Health requested detailed information on abortions in a form that could easily lead to the identification of individual patients. He wrote, "All too often the government asks for information it does not really need in the pursuit of better public health."

EMPLOYEES' HEALTH RECORDS

The National Commission on Confidentiality of Health Records has devoted a great deal of attention this past year to the need for new standards for the use of employees' health records. Confidentiality assumes extreme importance in the occupational setting, where loss of a job or a promotion opportunity can bring dire economic and emotional consequences.

Health information flows into the workplace through a number of channels, including job application forms, physicals taken by prospective employees, evaluation, and treatment provided by the corporation's medical department, and claims submitted by employees enrolled in group health insurance plans.

What's more, occupational health records providing clues to environmental causes of illness are sought by NIOSH and OSHA for detection of hazardous substances in the workplace. As a result of comment from public groups, and particularly from our National Commission, on OSHA's proposed medical records regulations 29 CFR 1910.20, OSHA has developed confidentiality guidelines governing its collection, use and disclosure of employee medical record information.

But these employers' policies vary widely. Some corporations strictly insulate medical data from other records, while others still mix medical information with personnel records. Many employers still ask applicants whether they have ever received psychiatric treatments. Many employees fear that such medical information

provided to their employer will label them as a future financial risk to the company.

In a recent local court case in which we were involved, a Maryland social worker named Bonnie Cox Womeldorf successfully opposed the medical information requirements of the Montgomery County Welfare Department. This has been written up in the newspaper extensively. The pre-employment questionnaire contained such questions as "Have you ever had vaginal discharge?" and "Do you fear heights?"

They were questions quite irrelevant to the job she was seeking. She refused to give blanket consent to disclosure of her medical records. When she took steps to bring suit, the intrusive questions and blanket consent clause were removed in an out-of-court settlement, and the county made across-the-board changes in its handling of employee health records.

I think this case is especially important because it illustrates that if people do oppose an inappropriate action or requirement, if they have the patience and necessary legal help—and this individual did also receive help from the National Association of Social Workers and the mental health law project—they can succeed.

HEALTH RESEARCH AND HEALTH DATA BANKS

In regard to health research and health data banks, these have presented some of the more difficult balances between patient privacy and society's need to know. In general, research tends to receive special consideration when its information needs conflict with confidentiality. Some researchers have argued that research be given a privileged enclave status with relatively unrestricted access to medical records.

One would have doubt with regard to such an enclave. But, if it is created, we must carefully define its members and place an absolute prohibition on disclosures of research data for nonresearch purposes.

We must also assure that patient-identifying information is collected for a definite research purpose. When agencies collect information without adequate safeguards and without explaining why they need the information, it begins to appear as though as one of our correspondents put it, "the government is assuming a questionable big brother role."

A disturbing example of unauthorized disclosure of health research information occurred when New York State Health Department researchers conducting an abortion study financed by the National Institutes of Health, disclosed the names of some 28 women involved in a progress report to NIH. They even circulated partial names of women to the Department of Motor Vehicles to locate study subjects who had moved.

CHILDREN AND YOUTH

There are very special confidentiality problems where children and youth are concerned. These are too often neglected. Minors have real privacy interests that do not always coincide with the interests of their parents. It is also important to remember that

children have a long, unforeseeable future. Facts collected about the health of a 2-year-old may remain in his records for 70 years.

The family physician's or school health record often contains tentative diagnoses, unproven guesses, and developmental data which in the years to come may acquire an unwarranted patina of objectivity. For example, a child labeled with "minimal brain dysfunction"—or MBD—may have been experiencing slow motor development at age six; and this may have completely disappeared but remains in the record.

Of course, confidentiality is not always in the interests of a minor patient—not, for instance, when parents take steps to prevent evidence of child abuse or neglect from reaching authorities. On the other hand, we must remember that adolescents have a strong interest in confidentiality when they visit a clinic for birth control counseling, treatment of venereal disease, or other confidential services that the law entitles them to receive without parental consent. Letting parents know about such visits against the patient's wishes may interfere with the minor's right to privacy.

Above all, practitioners must be encouraged to respect a minor patient's need for confidentiality as something separate and distinct from the wishes of his parents.

PATIENT PARTICIPATION RIGHTS

As one of our patient correspondents said, "My health records are available for anyone's use or misuse except my own." The current patchwork of State laws—with some 13 States providing patients with access to their records in varying degrees—creates unnecessary confusion among the public. How can patients authorize access to their records by third parties, if they themselves do not know what the records contain?

When it is necessary to guard against the possibly harmful effects of allowing certain psychiatric or terminally ill patients to see their records, special procedures can be arranged. For example, a health professional designated by the patient can decide how much of the record a patient should see. But the need for special procedures in special cases should not get in the way of providing access, as a general rule, for those patients who request it.

Let me conclude.

I would say unequivocally that there is a real need for Federal medical privacy legislation for the following reasons:

First, we see only the tip of the iceberg in abuses of health records confidentiality.

Second, most patient-consumers are not aware of the uses of personal health information until they experience some direct economic harm or emotional embarrassment.

Third, the status of current State law is a polyglot of protections and access laws largely limited in coverage to State-run institutions.

Finally, the Privacy Protection Study Commission has documented the medical privacy issues and has recommended Federal legislation.

Any medical privacy legislation must address these broad questions:

Who has access to confidential personal health information and for what purposes?

What confidentiality safeguards are health recordkeepers expected to have?

What legal expectation of confidentiality is a patient entitled to and how will it be enforced?

By way of summary, we at the National Commission on Confidentiality of Health Records welcome your efforts to meet the needs for comprehensive legislation in four respects:

One, your bill, Mr. Preyer, provides patients with an explanation of providers' recordkeeping practices and patients' privacy rights.

Two, it provides patients with right of access to their health records.

Three, it makes patient consent standards more specific and detailed.

Four, it restricts nonconsensual disclosure of health records.

I want to thank the committee members for receiving my remarks this morning. I hope that this has contributed to your efforts and that at a future time we will be asked to comment on specific legislation.

I will be pleased to answer any questions that you may have.

Mr. PREYER. Thank you very much, Dr. Freedman. We appreciate your testimony today. It has been very helpful.

We will take advantage of your offer to contact you at a future time for comments on specific legislation.

I regret that we are running a little late today. Some of the questions that we might like to ask you we will have to ask later.

Let me ask you one question that is of concern to us. In the case of *United States v. Miller*, the Supreme Court held that an individual had no interest in his bank records held by a bank if the records were subpoenaed from the bank.

Does that ruling apply, in your judgment, to medical records as well as bank records?

Dr. FREEDMAN. I would like to ask our counsel, Mr. Belair, who has been working on this particular issue, to comment on that.

Mr. BELAIR. Our sense, Mr. Chairman, is that there is plenty of room for the court, if it wants to, to distinguish the bank records case from the medical records case.

As you know, in the *Miller* decision, the court said that bank records were not confidential information, not the private papers of the bank customer. We are hopeful that, in the medical context, the court would see fit to rule that these papers are in fact confidential, the records are the private property of the patient.

On the other hand, we are aware that in most States the law provides that hospital records are the property of the hospital.

We are also not encouraged by the Supreme Court's treatment of the medical records issue in *Whalen v. Roe*. In this case the Court seemed to suggest that, although there may be some very abstract right of privacy in medical records, at least in that case involving New York State's access to very sensitive drug record information, it was not terribly concerned with the State's collection of this information from a constitutional standpoint.

Therefore, it seems to us that your committee, sir, is very well founded in its concern that, in the absence of the Government

access safeguards that you have written into your legislation and that appear in the other two pieces of legislation, it might very well be that the court getting this question—and the Supreme Court, of course, has not spoken directly to this question as yet—might see *United States v. Miller* as a precedent.

Mr. PREYER. Thank you, Mr. Belair.

Mr. Kindness.

Mr. KINDNESS. Thank you, Mr. Chairman.

I have no questions at this point.

I appreciate your testimony today, sir.

Mr. PREYER. Mr. Weiss.

Mr. WEISS. Thank you, Mr. Chairman.

First I would like to add a word of welcome to Dr. Freedman, who has been not only a distinguished citizen but also a distinguished constituent of mine and a good friend for many years. I think that he has made a very, very valuable contribution to our consideration of the subject.

I guess I really have only one general area because I think the testimony really covers the subject very, very well.

That is this. What has the Commission noted—what have you individually noted about the concern of individual physicians who may be caught in this kind of “never-never land” of having to balance the rights of patients as against the rights of the Government or demanding agencies or organizations?

Dr. FREEDMAN. Overall, a great concern. Probably no issue at the present time is of greater concern to physicians in general, particularly for my own specialty of psychiatry.

Since the formation of the Commission, I have constantly been requested to address groups. They raise truly agonizing problems in this regard and also bring forth a number of problems—for example, the insurance forms. There is one I saw recently put out by an insurance company which asks such questions of the psychiatrist: Have you been trained in any psychoanalytic school? What psychoanalytic school was that? Was a transference effected with your patient? Describe some of the patient's fantasy life.

Questions of the nature of whether transference was effected were asked of the patient. I cannot see how this has anything to do with the reimbursement question. So, physicians are very troubled about that. Those in hospital practice are also perturbed about leakage of information or some of the loose handling of material in the hospital situation.

Problems of access are perturbing particularly for the psychiatrist. I think the position here is one that certainly receives support because, while patient access in most cases is no problem, psychiatrists do run into situations in which they feel it would be deleterious to the patient to see the record at a certain point in treatment—for example when in psychiatric practice, the physician or social worker interviews members of the family, gathering third-party information given in confidence. This may create enormous problems if the patient has access to all this material.

So, I would say confidentiality is a big problem. It is a problem for other physicians, those involved with venereal disease or abortion or cancer reports. They all find themselves beset by so many

records. Then the whole area of third-party payments, of course, is a very big question.

Mr. WEISS. I thank you very much.

As I say, the testimony has been very, very comprehensive and I think very helpful. I am sure that we will be calling on you as the occasion warrants and as we proceed in this legislation.

Thank you, Mr. Chairman.

Mr. PREYER. Thank you, Mr. Weiss.

Dr. Freedman, Mr. Belair, and Ms. Levin, we appreciate very much your being here today. While there are some other questions which we would like to get your wisdom on, I hope you will let us contact you about them a little later on, in view of the hour.

Dr. FREEDMAN. Thank you.

Mr. PREYER. The subcommittee stands adjourned until Monday at 10 a.m.

[Supplemental material submitted by Dr. Freedman follows:]

NATIONAL COMMISSION ON CONFIDENTIALITY OF HEALTH RECORDS

606 National Press Building Washington, D.C. 20045

(202) 347-0900

Executive Committee

ALFRED M. FREEDMAN MD
President and Chairman
ANN KAHN
Vice President and Vice Chair
ALAN M. BRENT
Treasurer
ELOISE M. AGGER MSW
Secretary
JEROME S. BEIGLER MD
HERBERT PARIS
HERBERT SACKS MD

Full Members

American Academy of Child Psychiatry
Director: HERBERT SACKS MD
American Academy of Pediatrics
Director: ARNOLD D. HODMANN MD
American Academy of Psychoanalysis
Director: HENRY A. SEGAL MD
American Hospital Association
Director: HERBERT PARIS
American Medical Record Association
Director: LORRAINE VOLZ RHA
American Nurses Association
Director: JOYCE K. LABIN RN MS JD
American Psychiatric Association
Director: ALFRED M. FREEDMAN MD
American Psychosomatic Association
Director: JEROME S. BEIGLER MD
American Psychological Association
Director: FRED STRASSBURGER PhD
Eli Lilly Association
Director: J. ANN SALADINO
Federation of American Hospitals
Director: LEON YOCHESON MD
Health Insurance Association of America
Director: ROBERT S. LONG MD
Mental Health Association
Director: HARRY EBELING
National Association of Private Psychiatric Hospitals
Director: WALTER H. WELLSBORN MD
National Association of Social Workers
Director: JOANNA J. WILSON
National Congress of Parents and Teachers
Director: ANN KAHN
National Federation of Societies for Clinical Social Work
Director: ELOISE M. AGGER MSW

Associate Members
American Academy of Occupational Medicine
American Academy of Psychiatry and the Law
Director: ROBERT L. SADOFF MD
American Group Psychotherapy Association
Director: JOHN F. GORRIELLO PhD
American Medical Society on Alcoholism
Director: SHEILA BLUME MD
American Occupational Medical Association
Director: BERNARD J. SCHUMAN MD
American Statistical Association
Director: JOSEPH L. FLEISS
National Council of Health Care Services
Director: REYNOLD P. FLOM MD
Planned Parenthood Federation of America, Inc.

Executive Director
KATHIE DAVIS SPINGARN
Research Director
ALAN F. WESTIN PhD LLB

MAY 28 1979

May 25, 1979

Honorable Richardson Preyer
U.S. House of Representatives
Washington, D.C. 20515

Dear Congressman Preyer:

In response to your request, I am pleased to submit answers to questions your staff has raised and a sampling of letters from our case file concerning the confidentiality of health records.

Also included is a list of some of the more comprehensive state medical privacy statutes. We are now preparing a more detailed reference to state citations and will forward it to you when completed.

Please let us know if we can be of further assistance. We look forward to working with you in obtaining appropriate and fair health privacy legislation.

Sincerely,

Alfred M. Freedman

Alfred M. Freedman, M.D.
President and Chairman

AMP:dws

M E M O R A N D U M

TO: Representative Richardson Preyer
Chairman, Government Information and
Individual Rights Subcommittee

FROM: National Commission on Confidentiality
of Health Records Staff

RE: Response to Subcommittee Questions

Privacy Awareness

The National Commission on Confidentiality of Health Records has received hundreds of letters over the past three years from patients, physicians, nurses, social workers, hospital administrators, attorneys, employers, unions, government officials, and insurers concerned about the confidentiality of health records. Generally, the largest proportion of letters raise issues regarding government access to health records for audit and quality-of-care review. The second largest group of letters raise privacy problems regarding third party payers. The remaining letters concern hospital and employer information practices, disclosure in court proceedings, school records, and the need for new medical privacy legislation.

While NCCHR has not made a systematic, empirical study, our correspondence and our impact on the media definitely support the conclusion that public awareness of health privacy has increased dramatically. After every news article identifying the Commission, we are deluged with mail from patients and providers describing health information abuses and showing concern for protection of confidentiality. A sample of our mail is attached. Shocked by the ease with which third parties have accessed their record information, some patients voice great skepticism about their privacy and the confidentiality of the doctor-patient relationship. Many also see the computer as a symbol of lost privacy and of "big brother" data banks. Our case file also includes a number of letters from patients who were denied access to their own records, and who feel frustrated, angry, and shocked that patient access is not a legal right in most states.

Federal vs. State Action

Federal health privacy legislation is sorely needed, as state law has not adequately protected the privacy rights of all U.S. citizens. Under a Ford Foundation research grant NCCHR conducted a one-year study of state and federal law affecting the management of health record information. We sought to gather those code provisions which authorize, require, or prohibit disclosure of patient record information held by a health care provider. We found that state health privacy law was an uneven patchwork of loosely worded confidentiality regulations. Few states had anything approaching comprehensive health privacy legislation,

and even those that did were generally limited protection to state-run facilities. Rhode Island, Illinois, and the District of Columbia have recently passed health privacy legislation (the latter two limited to mental health information), but the state legislative trend is slow and uneven. Only about a third of the states provide for some form of patient access to their health records, and even in those states, patients may have to resort to litigation in order to gain access.

Even if the performance of state legislatures in this area improved, no state law can restrict federal government access to records. See, for example, Securities and Exchange Commission v. First Tennessee Bank N.A. Memphis (W.D. Tenn. February 27, 1978). As federal access has raised some of the major privacy issues, leaving privacy to state legislation would fail to address a key aspect of the problem.

Federal action is also required to deal with today's interstate commerce in health information. The Multi-State Information System, for example, is a private computerized mental health data system handling data for facilities in six states, with headquarters in Orangeburg, New York. Insurers conduct their business nationwide, as do researchers, auditors, and even some health care providers, such as Kaiser Permanente. Today's patients move frequently; they can enjoy privacy rights in one state and lose them in another.

Many states provide in general language that "patient records shall be confidential" as part of health facility licensing requirements, duties of state facilities, or patient rights statutes. But they do not specify authorized disclosures or establish penalties for violations. In fact, what they mean is not clear, and we do not know if these vague provisions are even enforced.

NCCHR staff is now preparing a detailed inventory of state statutes affecting professional and institutional handling of patient health information. It will cite provisions covering public health reporting, health data registries, specialized treatment facilities such as alcohol and drug abuse centers, patient access, and recordkeeping and confidentiality requirements for licensing of health care facilities.

Very few states have a comprehensive approach to health records confidentiality--an approach including standards for patient access, record maintenance and safeguards, limited nonconsensual disclosures, and penalty for violations. The following are examples of states with such comprehensive statutes:

Rhode Island: 1978 R.I. Pub. Laws ch.297

District of Columbia: 1978 D.C. Act 2-292

Illinois: 1978 S.B.255

Michigan: Michigan Compiled Law Annotated §330.1748

New York (Nursing Homes): 1975 N.Y. Pub. Health (McKinney) §2805-e

Patient Confidence

There can be no doubt that the confidentiality of health records enhances patient confidence in physicians and hospitals. This is particularly true for psychiatric patients, whose treatment depends on trust placed in a mental health professional. Our NCCHR case letter file includes letters from irate patients embarrassed or economically harmed by disclosure of personal health information without their consent. These patients denounce the disclosure, the physicians, and the health care system for failing to provide the privacy protection to which they thought they were entitled.

Breaches of confidentiality erode the health care relationship and can result in patients hopping from provider to provider searching for truly private care. Most patients today depend on public or private insurance to meet their medical expenses; in return they virtually sign away their health privacy without real assurance that their health information will be kept confidential. (See attached article on Medicaid audits.)

Patient confidence also suffers when a patient is denied access to his records. If patient access was a universally recognized statutory right, available without litigation, patients would feel that their treatment was being conducted in the "sunshine," and would be able to monitor and evaluate their care. One possible result could be fewer malpractice suits and other costly litigation.

Attachments

ST. VINCENT'S HOSPITAL
AND MEDICAL CENTER OF NEW YORK



153 WEST 11th STREET
NEW YORK, N. Y. 10011
212-620-1234

July 20, 1976

Alfred M. Freedman, M.D., Director
National Commission on
Confidentiality of Health Records
1700 Eighteenth Street, N.W.,
Washington, D.C. 20009

Dear Dr. Freedman:

I recently read with great interest a newspaper account of your Commission's charge and work. You are to be commended for your efforts in this area.

I am writing at this time to acquaint you with the local, State and Federal medical data reporting requirements pertaining to utilization review. Briefly, in order to ascertain and ensure the "appropriateness" and "medical necessity" of services provided at St. Vincent's Hospital,

All Hospital charts - both inpatient and ambulatory care cases - are subject to photocopying requests from the various private insurance carriers. Often, the entire medical record is requisitioned and sent to the carrier as a requirement for claims payment.

Blue Cross requires the completion of a "Hospital Request for 'Continuation Benefits'" form at twenty-one day intervals for all their subscribers.

Both Medicare and Medicaid require the submission of extensive medical data on the Hospital billing forms (making them readily available and accessible to non-medical personnel both at the Hospital and at the Medicare and Medicaid offices) in addition to the previously referenced photocopy material. These data enable the development of medical profiles for both patients and providers

In partial fulfillment of the Medicare and Medicaid "Conditions of Participation," the Hospital subscribes to the Professional Activity Study - Medical Audit Program (PAS-MAP) of the Commission on Professional and Hospital Activities. CPHA requires the completion of an extensive abstract of each inpatient record. Once again, the goal is the development of patient/provider profiles.

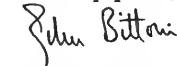
St. Vincent's Hospital has been awarded fully delegated review authority by the New York County Health Services Review Organization - the local Professional Standards Review Organization. NYCHSRO, too, requires the completion of an extensive discharge abstract for profile development.

The New York State Department of Mental Hygiene requires completion of the MS-5 "Admission and Termination Form" for psychiatric inpatients and outpatients.

In summary, both inpatient and outpatient records are subject to extensive scrutiny by all the various third parties and regulatory agencies. Increasingly, this is accomplished by means of machine readable chart abstracts which the Hospital must submit in order to be paid for services rendered.

I sincerely hope the above synopsis will be of some value to the Commission's work. Please do not hesitate to contact me personally if I may be of any additional assistance.

Sincerely yours,



John Bittoni
Department Head
Utilization Review

JB:tlh



Appalachian Hall

ASHEVILLE, N. C.
28603

March 25, 1977

WILLIAM RAY GRIFFIN, SR. M.D.
1905 - 1988

MARK A. GRIFFIN, SR. M.D.
1905 - 1988

WILLIAM RAY GRIFFIN, JR. M.D.

MARK A. GRIFFIN, JR. M.D.

ROBERT A. GRIFFIN, M.D.

Mrs. Pearl Honeycutt, Analyst
Benefit Review
Benefits Administration
Blue Cross/Blue Shield of North Carolina
P. O. Box 2291
Durham, North Carolina 27702

Dear Mrs. Honeycutt:

Enclosed please find medical records which include admission history, progress notes, doctor's orders and nursing notes for the hospitalization of Charles , Identification No. ; Confinement beginning January , 19 .

This set of records constitutes 115 pages of photo copies of the original record from date of admission to present (patient still hospitalized). 79 pages of the record are nurses' notes.

I realize the necessity of the review of records to determine liability under the FEP program. However, I seriously question whether or not all of these records are needed. Even Medicare, although requesting copies of history, progress notes, doctor's orders and discharge summary on every Medicare admission, does not request copies of the nurses' notes.

I also wonder when the various segments of the Federal Government will begin communicating with each other. As an arm of the Federal Government, you are requesting these 115 pages of medical records. It costs us between 3 and 4 cents per page for these Xerox copies, to say nothing of the time involved and the postage necessary to mail them. At the same time, the Executive branch of the Government and the Department of Health, Education and Welfare is asking Congress to put a cap on hospital rate increases. Some way or other, the right hand ought to know what the left hand is doing.

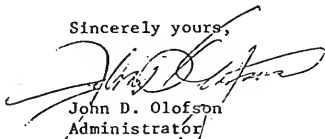
May I also speak to the subject of confidentiality. These records undoubtedly reveal the most intimate facts about the patient's life, as do all records from a psychiatric hospital. Even though they are marked "confidential" on every page, I literally cringe when I see records like these being mailed to FEP, Medicare and Champus. (I mention these three insurance programs specifically because it is very seldom that any commercial health insurer requests records.)

I wonder what happens to these records? Who reads them? Where are they placed after review? Who else might have access to them? Would you like all the intimate matters in your life exposed to who knows who or what?

This hospital has a Utilization Review Committee with two psychiatrists, who are not on our medical staff, serving as the physician members of the committee. All Medicare, FEP and Champus records are reviewed by this committee and each patient with these insurance coverages has a treatment plan and is assigned a length of stay according to the standards approved for this hospital by the North Carolina Department of Human Resources. If the original length of stay expires and the patient is still hospitalized, the attending physician must write an updated treatment plan explaining the need for further hospitalization and the Utilization Review Committee must again review to insure that continued hospitalization is appropriate.

With these procedures, why is it necessary to submit an entire medical record, which increases our costs and breaches confidentiality, and then have that chart reviewed by a non-physician clerk? I realize, Mrs. Honeycutt, that you are merely following standard operating procedures as passed down to you from Washington. Nevertheless, I feel so strongly about these matters that I felt I must protest --- and I assure you I will continue to do so until somebody listens, takes notice and does something constructive.

Sincerely yours,



John D. Olofson
Administrator

JDO:mh

cc: The President of the United States, Washington, D. C.

Mr. Joseph A. Califano, Jr., Secretary Health, Education and Welfare
Washington, D. C.

Thomas Bryant, M. D., Executive Director, National Committee on Mental Health
Washington, D. C.

Mr. James Gillman, Vice President FEP, 1800 M Street, Washington, D. C.

Mr. Tom Rose, President, Blue Cross/Blue Shield of North Carolina
Durham, North Carolina

Mr. Edward F.X. Lawlor, Jr., Executive Director, National Association of
Private Psychiatric Hospitals, 1701 K Street, Suite 1205, Washington, D. C.

Ms. Joy Midman, Associate Director, National Association of Private Psychiatric
Hospitals, 1701 K. Street, Suite 1205, Washington, D. C.

Alfred M. Freedman, M. D., President National Commission on Confidentiality
of Health Records, Inc., 1701 K Street, N.W., Washington, D. C.

PSYCHIATRY

NEUROLOGY

GERIATRICS

ORANGE COUNTY FLORIDA

ORLANDO, FLORIDA

DEPARTMENT OF SOCIAL SERVICES
ANNA M. LOVELL, MANAGER

MENTAL HEALTH REHABILITATION UNIT
2520 NORTH ORANGE AVENUE
ORLANDO, FLORIDA 32804

August 7, 1978

National Commission on Confidentiality
of Health Records
1211 Connecticut Avenue, N.W.
Washington, D. C. 20036

Dear Sirs:

I was very interested in seeing the letter of NDS, Executive Director, in an Ann Landers column, and am pleased to know that your agency exists.

My question pertains to mental health: Has your agency addressed the problem of mental health confidentiality and the complications that have arisen under the heading of accountability? In the state of Florida, this is still further complicated by the Florida Comprehensive Mental Health Act, commonly called the Baker Act; and by certain requirements of Health and Rehabilitation Service under reorganization. Among the latter are the Client Information System which will ultimately require the listing of name and social security number of all persons seen in the Emergency Room for psychiatric screening (as does Title XX for all states) for purposes of "tracking" that person (client) through all possible services throughout the state. Another requirement, which may not be unique to Florida, is that of referring client information according to "catchment" areas where community mental health centers are involved.

Releases from clients are required, of course, but as we all know, all of this documentation and accounting for and shifting around of information through so many clerical as well as professional hands, lends itself all too readily to breaching confidentiality.

If you have addressed the matter of confidentiality for mental health clients, I would be most interested in knowing what conclusions, suggestions and directions you may have reached. Thank you.

Sincerely,

Jane M. Staly
Jane M. Staly
Supervisor
Orange County Mental Health
Rehabilitation Center

JMS/fs



PLAINFIELD,
NEW JERSEY 07061
201-668-2220

OFFICE OF THE DIRECTOR
EDWARD J. DAILEY, JR.

August 5, 1976

Dr. Alfred M. Freedman
Chairman
National Commission on Confidentiality
of Health Records
1700 18th Street NW
Washington, D. C. 20009

Dear Dr. Freedman:

I read with much interest the article in the New York Times of 15 July 1976 in which your Commission appeals for information on incidents involving the violation of patients' privacy through the release of medical records by hospitals, physicians or other sources.

A trend which greatly concerns the trustees, administration and medical staff of this hospital is the increasing demand by government agencies for personal and social data, usually for well-intentioned research studies but all too often through methods which expose many details in the lives of private citizens. When these studies are published, or fed into a computer, or merely kept at the fingertips of a civil-service busybody, the dangers of invasion of privacy are greatly magnified.

A few specific examples in which government is assuming a questionable "big brother" role are these. . .

1. Birth Certificate Information

The birth certificate application form prescribed by the U.S. Department of Health, Education and Welfare, Public Health Service, National Center for Health Statistics (PHS Publication 1704) asks for the following data regarding both mother and father of the child:

Full name
Age at time of delivery
Birthplace
Race (White, Negro, American Indian, Chinese, etc.)
Education (Highest grade of school finished)
Proposed name of child
Complete address, including whether in the city limits



A COMMUNITY TEACHING HOSPITAL
AFFILIATED WITH THE COLLEGE OF MEDICINE AND DENTISTRY OF NEW JERSEY - RUTGERS MEDICAL SCHOOL

In addition, the mother is asked five more questions:

How many children are still living?
 How many were born alive, but are now dead?
 How many were born dead?
 What was the date of the last live birth?
 What was the date of the last fetal death (Stillbirth)?

A sample of this form is attached.

You will note that the form explains the many purposes to which a birth certificate is used and states that "these items are confidential information which will be used for medical and health use only." However, it is obvious that the facts are fed into a computer at the national level.

Here in New Jersey, the State Department of Health has also computerized such data as (1) the month of pregnancy in which prenatal care began, (2) the total number of prenatal visits and (3) whether or not a blood test for syphilis was made during pregnancy and, if so, the approximate date of the test.

Some of this data may very well serve a useful purpose in the reporting of vital statistics and may also serve as a guide in directing health care to critical areas, but it also constitutes further evidence of the mounting mass of personal and social information now being stored in computer banks. The chances of this highly personal data becoming available to others would seem to be considerable.

2. Abortion Records

This hospital is currently engaged in a disagreement with the State of New Jersey Department of Health concerning certain information requested on monthly "abortion/induced pregnancy termination reports." We believe the requests of the Health Department constitute an even more flagrant disregard of patients' rights than the information we are required to give on birth certificate application forms.

We are asked to report the following information on each abortion or induced pregnancy case:

Case number
 Date of abortion
 Gestation period at termination (number of weeks)
 Method of termination

We have no argument with the above and have reported these statistics. However, we believe that the following information requested by the Department represents an invasion of privacy by creating a personal profile which can easily result in the

identification of the mother, even though the actual names are not involved.

Age
 Marital status
 Residence (city, county, state)
 Race or ethnic group
 Prior number of pregnancies
 Prior number of live births
 Prior number of induced pregnancy terminations

Although names are not included in the abortion records, someone with access to these records could, in many cases, deduce the identity of the parent. This is particularly true in small communities where the number of abortions would be fewer than in large cities.

The New Jersey Attorney General does not interpret the requested information on abortions as violating the right of privacy of the individual. We feel otherwise and, on the advice of legal counsel, have declined to submit that information which we believe might jeopardize the identity and rights of those involved. Throughout the hospital stay of the abortion patient, all possible steps are taken to protect the patient's privacy, and we believe the State of New Jersey should be as judicious and careful in its own recording of personal data.

A copy of the State's Abortion Report and pertinent correspondence are attached.

3. Cancer Studies

A less clear situation but one that may place hospitals in a precarious legal position is the growing demand by the public for more information on the causes of various types of cancer. The government, responding to this need, is conducting an increasing number of in-depth surveys of environmental factors involved in the incidence of cancer. This, of course, requires close attention to many details in the private lives of patients.

The State of New Jersey Department of Health has instituted a statewide study on cancer of the bladder, which involves the review and photocopying of numerous medical records. If it becomes necessary to contact persons directly, prior approval will be obtained from attending physicians, according to a statement from the Department of Health.

The concern of physicians and hospitals that this could lead to possible litigation by patients' families has caused the State Attorney General to issue a detailed defense of the practice. The Attorney General has concluded that "such inspection by the Division violates no constitutional or legal rights of the facilities, physicians or patients." The Attorney General states further that such inspections of records "for purposes of public health research do not result in the breach of a health care facility's duty of confidentiality to its patients nor do they violate any personal rights of privacy even when conducted without the consent of the patients."

The conclusion is well documented with data on previous legal cases. I think you will find the Attorney General's findings and conclusions of particular interest to your Commission, as undoubtedly more and more conflicts will result as the number of studies relating to cancer and other diseases are stepped up throughout the nation. The statement is attached.

In addition to the three specific cases described above, the New Jersey State Department of Health has now initiated computer abstracts of all patients. We do not think we can legitimately oppose this but we do not favor the program. Presumably the information will be used (as in the cancer studies) in developing a profile documenting certain illnesses, but here again we believe the surrender of personal files to the State constitutes an invasion of the individual's privacy.

All too often, we believe, the government asks for information it does not really need in the pursuit of better public health. It also occurs frequently in the settlement of claims, including hospital payments, as in the requests by Medicare and Medicaid representatives for photocopies of detailed personal data, including nurses' and social workers' notes, which may pertain to a patient's mental condition, or other information which could endanger his or her employment or social relationships with others.

Muhlenberg Hospital is quite conscious of the possibility of leaks of confidential information, either intentionally or inadvertently. We have a strict policy that personal information about a patient or former patient, including all the facts of the patient's medical records, must not at any time be divulged to anyone other than the physician who is diagnosing, treating or consulting in the patient's case, or a government representative, police officer or attorney who presents the proper credentials and reasons for the request.

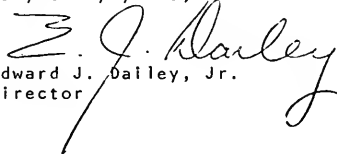
Our personnel must constantly make decisions on whether requests for information that appear to be legitimate are rightly so. People posing as physicians, who may in reality be insurance investigators or just curious relatives or "friends," often request highly personal data.

We have had requests from separated persons for the medical details of their spouses, and from unwed couples attempting to prove or disprove paternity. Recently a man asked the hospital for the blood type of a child. When the request was denied, he had a woman pose as the child's mother and make the same request. Because of the likelihood of other incidents such as this, the hospital never releases personal information by telephone. Often a subpoena is necessary before such information can be given out.

Many other examples exist in hospitals of real or potential violations of the right of privacy. I am sure that a more detailed study of our own hospitals' experience would produce additional cases of possible interest to your Commission. However, in the interest of expediting your research, I have forwarded these incidents as promptly as possible.

I wish you success in your study and would appreciate your sending me a copy of any reports which you believe might be of interest to us.

Very truly yours,


Edward J. Dailey, Jr.
Director

EJD:jp
Attachments



UNIFORMED FIREFIGHTER'S ASSOCIATION

of the Village of Scarsdale, Inc.

P.O. BOX 61

SCARSDALE, NEW YORK 10583

ALWAYS READY



ALWAYS ALERT

National Commission on Confidentiality of Health Records
1211 Connecticut Avenue
Washington, D.C. 20036

June 1, 1978

To whom it may concern,

I am writing to your organization at the request of the members of our association which represents the fire fighting force of the Village of Scarsdale, New York. I will try to consolidate the member's questions for you as briefly as possible.

First; Approximately three years ago, the "Village" mandated that ALL fire fighters will receive an annual physical exam, which is administered by a local physician and his staff at the Medical Center in Scarsdale. This exam is paid for in full by the "Village" (at a cost of approx. \$95.00 per man) and is quite extensive and thorough. The justification for the exam is obvious, however a majority of the members feel it is an infringement of their rights, in the way the exam and it's findings are handled. The most common "gripe" is that the results of the exam are kept on file in each man's personal record and are easily available for inspection by many if not all Village administrators and their staff, whether or not the person handling the file has anything to do with medical or fire department business. Question: Who may have access to these records and how are they to be kept secure?

Second; In line with the above, can a member tell the examining physician he (the member) does not want any of the findings, positive or negative, released to the "Village", only that he is fit or unfit to perform his job as required? Could a member refuse any findings whatsoever to be given to the "Village"?

Third; A member is not given a copy of the exam, however one will be mailed to his family physician if requested. In the same light, a member is given the right to have his own physician examine him (as per "Village" instructions as to which test are to be given) however a copy of the exam MUST be forwarded to the Village. Once received the "Village" will pay all costs up to \$95.00. NOTE: On an individual basis the exam and test usually costs about \$140 to \$150. If the "Village" does not receive the results as requested it may subject the member to disciplinary action. Can one refuse to submit the finding to the "Village" on the premise on doctor/patient relation?



UNIFORMED FIREFIGHTER'S ASSOCIATION

of the Village of Scarsdale, Inc.

P.O. BOX 61

SCARSDALE, NEW YORK 10583

ALWAYS READY



ALWAYS ALERT

Forth; May copies of an individual's exam be sent to medical insurers or other agencies which the "Village" is associated with, without prior approval of the individual? How can this be prevented as in the first question I asked?

Fifth and lastly; May the findings of an exam, which may not affect job performance be used against a member, and may that member be given a certain time to correct the problem or face possible disciplinary action?

There are a great many more related questions which have come to my attention, however with the basics I have given you, I'm sure you can figure about what they are in reference to. In your opinion what is the legality of the exam and how the results are handled? Also any comments or related information would be appreciated. If possible, when you reply, please send a copy of your reply to my home address listed below as well as to our organization's P.O. box. (Please mark envelope ATTN W.F. FELICE). Again, thank you for any information which you may give us.

Sincerely,

Walter F. Felice - Sect'y

(HOME) RD 3 107a Ooscawana Lk Rd.
Putnam Valley, New York, 10579

Employers

National Association of Letter Carriers

BRANCH 4607
FREMONT, CALIFORNIA 94537

National Commission on Confidentiality
of Health Records
1211 Connecticut Ave., N.W.
Washington, D.C. 20036

April 30, 1978

Dear Sirs,

Our members have been faced with a frustrating and recurring problem involving members of your organization. Supervisors in the U. S. Postal Service have taken it upon themselves to contact the physicians of employees who have submitted medical certification for extended absenteeism due to illness or injury. Upon phoning the doctor, they ask rather intimate questions regarding the employee's physical condition. The supervisor always has received this information with little or no question. On several occasions the supervisors inferred that the patient was in danger of losing his job if he could not return to work promptly- whereupon the doctor, believing he was helping the patient, changed his prognosis to suit the Postal Service's needs.

We are appalled that such information is given so freely over the phone. Are we incorrect in the belief that the doctor-patient relationship is supposed to be private? Are not the doctors and/or their assistants wrong in releasing or discussing this information without the consent of the patient?

We are planning to distribute a printed form to our members which instructs/ the attending physician not to discuss his condition with anyone without written permission. The employee would give this form to the doctor if and when he receives treatment. Is this proper?

We would appreciate any opinions or suggestions you can give on the aforementioned matters. A prompt response would be most beneficial to our members.

The above letter was sent to the AMA and the CMA, they didnot give us much to go on. Would appreciate anything you could do for us.

Sincerely,

Delite Askelson,
secretary

DONALD L. HILTZ, R. P. T.
CHARLES A. KIBBEY, R. P. T.
RALPH L. SHERWOOD, R. P. T.

PHYSICAL THERAPY

WHITEFLINT PROFESSIONAL BUILDING
11119 ROCKVILLE PIKE
ROCKVILLE, MARYLAND 20852

PHONE: 881-3443

FOXHALL SQUARE BUILDING
3301 NEW MEXICO AVENUE, N. W.
WASHINGTON, D. C. 20016

PHONE: 966-7111

November 23, 1977

Natalie D. Spingarn, Director
National Commission on Confidentiality
of Health Records
1211 Connecticut Avenue, N.W.
Washington, D. C.

Dear Ms. Spingarn:

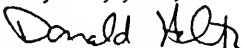
In February, 1977, I was called by Mr. William Rhoda, who is with the Division of Licensing and Certification in the Maryland Department of Health and Mental Hygiene. He informed me that my Whiteflint office would be surveyed on April 28, 1977, by Mr. Robert Schwartz. The purpose of this survey was to determine by compliance with Federal Regulations governing Medicare.

During the survey, Mr. Schwartz indicated he wished to review records of patients not covered by Medicare. I might add at this point that the Medicare form which patients sign contains an authorization for review of their records by officials of the Social Security Administration. Obviously, Mr. Schwartz had no such authorization to review any other files or patient records. This being the case, I refused him access to any records, other than those covered by Medicare. He cited the State Operations Manual, section 2480.5 which gave him the authority to examine any records which he picked at random. Nevertheless, I still felt, and still feel, that patients' records are confidential and cannot be examined without their express written consent. He was not allowed to review any records other than those for which he had the patients' permission.

I learned two weeks ago, from Mr. Schwartz, that my Medicare certification was not going to be renewed because of my refusal to open my records to the survey.

I have written to Congressman Steers and asked his assistance. I now appeal to you for help also. It is incomprehensible to me that this situation has arisen. It is impossible for a practitioner to adhere to professional ethics and standards of practice and maintain certification with Medicare. If this does not represent invasion of privacy by the Federal government, what does????

Very truly yours,



Donald L. Hiltz, R.P.T.

DLH/rmc

22
DONALD L. HILTZ, R. P. T.
CHARLES A. KIBBEY, R. P. T.
RALPH L. SHERWOOD, R. P. T.

PHYSICAL THERAPY

WHITEFLINT PROFESSIONAL BUILDING
11119 ROCKVILLE PIKE
ROCKVILLE, MARYLAND 20852
PHONE: 681-3443

FOXHALL SQUARE BUILDING
3301 NEW MEXICO AVENUE, N. W.
WASHINGTON, D. C. 20018

PHONE: 956-7111

December 12, 1977

Natalie D. Spingarn
Executive Director
National Commission on Confidentiality
of Health Records, Inc.
1211 Connecticut Avenue, N.W.
Washington, D. C. 20036

Dear Ms. Spingarn:

I received your letter of December 6, 1977 regarding my problems with Medicare. I sincerely appreciate your efforts on my behalf, and on behalf of my patients who do not wish their records opened before Federal surveyors without their consent.


I have contacted the local chapter of the A.C.L.U. and have been advised that they feel that this represents a violation of civil liberties. The local chairman, Gary Simpson, has written me and advised that one of their attorneys will be in touch shortly.

In reply to your question regarding my letter, I would be most happy to have you use my name. I would be available to personally testify because I have such strong feelings in this area.

If the government is allowed to invade records as it chooses, George Orwell's 1984 will be upon us long before then. The thought of that actually occurred frightens me.

Thank you again for your cooperation and assistance.

Very truly yours,



Donald L. Hiltz, R.P.T.

DLH/rmc

DONALD L. HILTZ, R. P. T.
CHARLES A. KIBBEY, R. P. T.
RALPH L. SHERWOOD, R. P. T.

PHYSICAL THERAPY

WHITEFLINT PROFESSIONAL BUILDING
11119 ROCKVILLE PIKE
ROCKVILLE, MARYLAND 20852
PHONE: 681-3443

FOXHALL SQUARE BUILDING
3301 NEW MEXICO AVENUE, N. W.
WASHINGTON, D. C. 20016
PHONE: 986-7111

January 16, 1978

Ms. Natalie D. Spingarn,
Executive Director
National Commission on Confidentiality
of Health Records
1211 Connecticut Avenue, N.W.
Washington, D. C.

Dear Ms. Spingarn:

On Wednesday, January 11, 1978, I participated in the filming of a segment to be aired in March. Paul Sandenman contacted me in this regard, apparently after being referred by you.

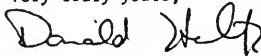
Interestingly, on January 12, 1978, William Rhoda from the State Department of Health and Mental Hygiene called to advise that I had been recertified by Medicare. I have, of course, contacted the T.V. station because of this sudden change in posture on the State's part.

For whatever the reason, Medicare has decided that I may continue to be reimbursed for my professional services. Perhaps the heat was too great, but, nevertheless, the government still feels that it has the right to review patients' records without the consent of the patients.

I am personally glad this entire matter is over. However, the problems remain and will probably crop up again next year during the survey.

Please keep up the good work. If I may be of any assistance, please feel free to call upon me.

Very truly yours,



Donald L. Hiltz, R.P.T.

DLH/rmc

DRUG ABUSE REHABILITATION SERVICES:

- MENTAL HEALTH CLINIC (DRUG-FREE);
- METHADONE MAINTENANCE TREATMENT;
- SU CASA: DAY AND RESIDENTIAL METHADONE-TO-ABSTINENCE REHABILITATION;
- COMMUNITY PREVENTION & EDUCATION

Edward M. Brown
Executive Director
Herbert Barrish, C.S.W.
Assistant Director
Kevin Quinn
Administrator

March 20, 1978

Ms. Toby Levin
National Commission on Confidentiality
of Health Records
1211 Connecticut Avenue, N.W.
Suite 504
Washington, D.C. 20036

Dear Ms. Levin:

As you are aware from our phone conversation, this agency has just undergone a site visit from a Performance Review Team from one of our funding agencies, the New York State Office of Drug Abuse Services. Our records have been read in the past year by:

- a three person team from the New York City Medicaid Department of Social Services
- a representative from the New York State Department of Mental Hygiene
- a representative from the New York City Substance Abuse Services Office (funding support)
- our contract manager from the New York State Office of Drug Abuse Services (funding support)
- four members of the above mentioned Performance Review Team

Granted that funding agencies have a right to inspect records, but it seems to me that opening records to ten people in the course of one year makes a mockery of confidentiality.

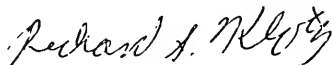
We are also concerned with the qualifications of the reviewers. They generally lack professional training and the attendant emphasis on ethical standards. Only the representative of the New York State Department of Mental Hygiene held a license or certificate

in a mental health profession out of the ten individuals mentioned.

I would like to share one example of the naive, almost primitive quality of some of the individuals who have access to our records. There was considerable giggling at the description of our clients psychotic symptoms by the members of the Performance Review Team. It is indeed worrisome that individuals so unacquainted with the field can read records. Who knows what gossiping went on when they reached home? Who knows what punitive reactions of anger and disgust at our clients anti-social behavior could occur? Who knows what personal advantage might be taken of clients upon discovery of compromising situations such as that of an ex-prostitute client now in graduate school? I do not.

We are writing to ask that your organization address itself to these two issues. We would also appreciate it if you can help us discover any legal remedy to this situation or standardized criteria for case file monitors and reviewers.

Sincerely yours,



Richard S. Klotz, M.S.
Clinic Administrator

RK/rw

cc: Edward Brown
Herbert Barish

NATIONAL COMMISSION ON CONFIDENTIALITY
OF HEALTH RECORDS
1700 18TH STREET NW
WASHINGTON, DC 20009

DEAR SIRs:

I APPRECIATE THE OPPORTUNITY TO HAVE SOME INPUT INTO YOUR PROCEEDINGS. A POINT THAT I THINK THAT WOULD BE WORTHY OF YOUR CONSIDERATION IS THE RELATIONSHIP OF THE PRIVATE PRACTITIONER TO LOCAL WELFARE DEPARTMENTS AND THE WELFARE DEPARTMENT'S RIGHT TO ACCESS TO MEDICAL RECORDS ON THE WELFARE CLIENT. SPECIFICALLY A FREQUENT EVENT IN MY LOCAL AREA AS A PRIVATE PRACTITIONER OF PEDIATRICS IS FOR ME TO RECEIVE A PHONE CALL FROM A PERSON WHO IDENTIFIES THEMSELVES AS A MEMBER OF THE DEPARTMENT OF PUBLIC WELFARE AND WHO ON THE TELEPHONE REQUESTS INFORMATION REGARDING RECENT MEDICAL CARE GIVEN TO A WELFARE PATIENT WHO IS A RECIPIENT OF EITHER MEDICAID ASSISTANCE OR MEDICARE SUPPLEMENTAL SECURITY INCOME ASSISTANCE. I FIND THIS A VERY AWKWARD REQUEST TO ANSWER ON THE TELEPHONE SINCE I HAVE NO DIRECT AUTHORITY FROM THE PATIENT THEMSELF AND SINCE THIS INFORMATION IS OFTEN PREJUDICIAL IN MY OPINION TO THE PATIENT'S INTEREST. IF WE WERE TO RELATE THIS TO THE PRIVATE SECTOR OF OUR ECONOMY, AN INSURANCE CARRIER REQUESTING INFORMATION ON A PATIENT WOULD BE REQUIRED TO PROVIDE A SIGNED AUTHORIZATION FOR THEM AND THIS WOULD HAVE TO BE IN MY HANDS BEFORE I WOULD RELEASE INFORMATION TO THE INSURANCE CARRIER. IT MAY WELL BE THAT THE WELFARE CLIENT HAS GIVEN THE WELFARE DEPARTMENT THE AUTHORITY TO SEEK INFORMATION, HOWEVER, I HAVE NO COPY IN MY HANDS AT THE TIME THIS INFORMATION IS BEING SOUGHT AND I THINK THAT THIS PROCEDURE NEEDS CLARIFICATION. AS IT STANDS AT THE MOMENT, I GENERALLY DECLINE TO GIVE OUT THE INFORMATION AND SOMEHOW THE WELFARE DEPARTMENT GENERALLY FOUND THEMSELVES ABLE TO LIVE WITHOUT IT.

ANOTHER SPECIFIC AREA THAT I FIND TO BE ABUSIVE OF PATIENT CONFIDENTIALITY IS WHEN THE STATE DEPARTMENT OF WELFARE OR SOME BRANCH OF THE DHEW SENDS A LETTER TO ME REQUESTING INFORMATION REGARDING RECENT GOVERNMENT SUBSIDIZED PATIENT VISITS, AND THERE IS NO ACCOMPANYING AUTHORIZATION FORM FOR ME TO RELEASE INFORMATION TO THAT BUREAU. AGAIN, I GENERALLY DECLINE TO RELEASE THE INFORMATION AS I WOULD IF I WERE DEALING WITH A PRIVATE INSURANCE CARRIER.

I WOULD APPRECIATE THE COURTESY OF A RESPONSE TO THIS LETTER AND WOULD ULTIMATELY WOULD HOPE TO BE ABLE TO SEE A COPY OF YOUR RESULTS OF YOUR PROCEEDINGS.

I WISH YOU SUCCESS IN YOUR ENDEAVORS.

SINCERELY YOURS,

July 15, 1976

Alfred M. Freedman, M.D.
1700 18th Street N.W.
Washington, D.C. 20009

Dear Dr. Freedman,

I have had two unwarranted intrusions upon the confidentiality of my medical records over the past three years. The _____ insurance Company, who are the agents for Medicare in this state has had two intensive reviews of my patients medical histories in what they claim was a search for utilization review. The last occasion, approximately one year ago, they photocopied every page of the records of ten patients. I consulted my lawyer who told me that I had no choice but to co-operate since the signing of the claim form for payment was an automatic release of information. This is obviously a ~~quotation~~ "Catch 22" in that unless a form is signed, the patient or the doctor cannot be repaid. If the form is signed, an automatic release of information against my better judgement is required. I do hope this information will be of assistance to you.

Respectfully yours, _____

M.D., P.A.

MS/bop

October 5, 1977

Natalie Davis Spingarn
National Commission on Confidentiality of
Health Records, Inc.
1211 Connecticut Ave., N.W. Suite 504
Washington, D.C. 20036

Dear Ms. Spingarn:

I am writing to you to detail one of the most outrageous violations of civil rights and private patient medical Records confidentiality in existence today.

A conflict exists in the State of Illinois between the Illinois Department of Public Aid and the physicians of Illinois. Basically, Illinois physicians have insisted on written release from the patient for the date of visit in question when medical records are requested by the Illinois Department of Public Aid for review in audit. The State's position is that no such release is required. Litigation is pending in several law suits filed against the state on this issue. The Illinois State Medical Society has filed Friend of the Court Briefs in favor of protecting confidential medical records.

In Illinois, no such release or documentation has ever been obtained, and the state is absolutely wrong, we feel, in their position. They have used coercive powers including the threat of suspension and termination from the Medicaid program to force Illinois physicians to give up these medical records. The problem is more acute because political hacks, retired policemen, and other non-professional--unprofessional individuals have received access to these records and have reviewed them in medical offices around the state. Further, random Xerox copies of medical records have been made in the medical offices without permission and without knowledge of Welfare recipients, and taken from the premises.

In Illinois, as in other states, no one questions the right of government to insure that it gets what it pays for. On-going audits are excellent, if properly carried out. In Illinois, these audits have been the subject of much controversy, since they involve the illegal search of medical records by incompetent, untrained medical personnel, - un-

Natalie Davis Spingarn
Page Two

October 5, 1977

skilled in review of complex medical data. Further, no protective mechanism exists for protecting the confidentiality of these records. Last, but not least, patients are unaware that records of their venereal disease, marital infidelities, occult cancers, and other confidential records are being indiscriminately bantied around the state.

In Illinois, considerable documentation exists that suggests that the audit procedure is unprofessional, token, and done strictly to attempt to meet HEW requirements.

Many physicians in Illinois feel that if an audit is being performed, and if the expense of such an audit is to be undertaken, little extra cost is obtained if written releases from patient's records being audited is obtained in advance. No substitute for this protection exists.

It is interesting to note that no where in private industry or in Medicare does the principle of giving away in advance, for specific period of time, the confidentiality of one's medical record.

I've enclosed a letter of August 11, 1977, from the Director of the Illinois Department of Public Aid to the Regional Commissioner of HEW. This record documents the position of the State and requests HEW's approval for one of the most precedent-setting and offensive assaults on confidential medical records. This proposal would require any Medicaid recipient to sign away, in advance, the release of, and the confidentiality of his medical record for the month he receives his Medicaid card. Refusal to do so would result apparently in ineligibility for Medicaid. The Ad Hoc Committee on Public Aid to the Chicago Medical Society has gone on record as being extremely upset with this proposal. The Illinois Department of Public Aid has worked out this method of alleviating medicine's concern over the release of these records in this shallow, callous fashion.

Many of us in Illinois will be working long and hard to defeat this proposal. Any help you can give us would, of course, be appreciated. Please remember again that Illinois physicians believe government is entitled to review records in an attempt to audit proper payments. It is not too much to request written release from a patient for the date of visit in question. It is not too much to ask government to take that small step to protect the patient and to give him the opportunity of refusing to release sensitive personal data to the vast federal bureaucracy and its incredible computer system.

Sincerely,

December 4, 1978

Ms. Natalie Spingarn, Executive Director
The National Commission on Confidentiality
of Health Records, Inc.
Suite 504
1211 Connecticut Ave., N.W.
Washington, D.C. 20036

Dear Ms. Spingarn:

In October 1978 the Executive Board of the New Jersey Psychological Association formed a committee on the Utilization of Professional Services to represent the profession of psychology in New Jersey in its contacts with the various state agencies and state programs which utilize psychological services. One of the programs we have been very involved in is the New Jersey Medicaid Program administered by Mr. Thomas Russo, Director, Division of Medical Assistance and Health Services in the Department of Human Services.

In the process of exploring a number of problems which have arisen between the members of our profession and the administrators of the Medicaid program, it occurred to us that there may well be legal issues involved with which you may wish to concern yourselves. Briefly, these appear to be issues of:

- 1) the violation of the Medicaid client's right to confidentiality as provided under the 1968 Psychology Licensing act
- 2) issues involving informed consent
- 3) issues involving due process
- 4) issues involving self incrimination.

We are concerned that certain civil rights of Medicaid clients, as consumers of mental health services, are being violated and that certain civil legal rights of psychologists are being violated.

The Division of Medical Assistance and Health Services contains an office of integrity which has a watch-dog function to prevent abuse,

fraud, etc. When its computer indicates that a particular practitioner is providing services in a pattern which is different from other providers, the office of integrity may send a field investigator to the office of the practitioner to validate that the services which were claimed were in fact provided. The claim form (a sample is enclosed) contains two items: No. 16, patient's certification, and No. 17, provider certification, which apparently give the investigator the right to examine the records of the practitioner including the personal folder of the client.

The practitioner is not eligible for reimbursement unless both certification items are signed and the client is aware that the practitioner will not continue to provide services to that client unless the claim form is signed. In certifying that the services were performed as billed for, both the client consumer and the practitioner appear to be forced into waiving their rights to confidentiality which the 1968 Psychology Licensing Act guarantees.

Thus, when a field investigator conducts an audit of a practitioner, the psychologist feels in fear of legal consequences if he does not cooperate in showing all records requested; these may also include records (e.g. appointment calendars) which contain the names of non-Medicaid clients. The rights of the provider in refusing to make certain records available is not explained. In fact, none of the rights of the patient or provider are ever explained.

The progress notes of a psychotherapist, whether psychiatrist, psychologist, psychiatric social worker, or pastoral counselor have traditionally always been regarded as a private and confidential personal record for the practitioner himself and NOT as a public record or as a communication to others. In that sense there is a significant and fundamental difference between the records of an independent psychotherapist in a private office and a medical chart in a hospital. There is extensive precedent establishing the importance of and the legal protection given to a patient's right to confidentiality.

Yet, the field investigator apparently has the right to demand to see these confidential progress notes and to make a judgement as to whether these records are sufficient to document the actual provision of service. The length, detail, legibility, or any other aspect of a therapist's private progress notes are not a valid measure of the extent of or quality of service provided. Indeed, many therapists have learned not to keep any progress notes at all as a way of insuring their patient's rights to privacy; these practitioner's are being judged as failing to keep proper records and are subject to administrative action by the Medicaid program (which can range from a warning, through suspension, suit for recovery of funds, to legal action).

The data obtained from the field investigation is reviewed and if there seems to be evidence of illegal practice, the field staff report is turned over to the Legal Action Committee of Medicaid. A deputy attorney general is present at these meetings and may decide he wants a case referred to the Division of Criminal Justice for further review. Once the Division of Criminal Justice decides to take a case for possible criminal prosecution, Medicaid no longer has jurisdiction over the case and its final disposition. In fact, Medicaid is prohibited by the attorney general's office from advising the provider in any way that his case is under investigation by the Division of Criminal Justice and that he may be prosecuted or that investigative findings may be turned over to a grand jury.

We feel that the issues involved - right to confidentiality, invasion of privacy, informed consent, and due process - are extremely important; that only a particular segment of the population if subjected to these circumstances makes it seem especially important. We will appreciate your response to these matters and whether your office feels our concern is justified and, if so, how we can aid in facilitating corrective action. Thank you for your help in this matter.

Very truly yours, -

DAVID C. WILSON
Neuropsychiatric Hospital

June 15, 1977

Owen W. Brodie, M.D.
President, Neuropsychiatric
Society of Virginia
1500 Westbrook Ave.
Richmond, Va. 23227

Dear Owen:


In the course of our recent dealings with Blue Cross and Blue Shield, we have recently encountered a problem which might well deserve the consideration by the appropriate committee of the State Society as well as the Virginia Chapter of the NAPPH.

Blue Cross and Blue Shield has recently advised us that they plan to audit all hospital charts over a three month period (but only from hospitals who submit their claims "manually") and that they will withhold payment on these claims until these audits are completed. In most instances, they have requested copies not only of the admission histories and discharge summaries but also of all progress notes. Obviously, this will play havoc with our cash flows system. From a clinical standpoint, I am concerned about the extent and nature of confidential material which will be released, presumably for routine review and screening by lay personnel in the Blue Cross offices. I am sure that Blue Cross' request is legally justified in that patients do sign the usual authorization for release of information. I rather doubt, however, if this is indeed an (informed consent) in that patients are aware of the extent and nature of the highly personal information which is thereby made available to others. From a professional standpoint, I would suggest that this particular problem be brought to the attention of the insurance

committee of the Neuropsychiatric Society of Virginia for their consideration. From the standpoint of the 11 private psychiatric hospitals in Virginia (at least those which admit patients covered by the Richmond Blue Cross plan), I would think this matter would be of equal concern to the Virginia Chapter of the National Association of Private Psychiatric Hospitals.

Thanking you for your consideration of this matter, I remain, with all best personal regards,

Most sincerely,


William M. Sheppe, Jr., M.D.

WMS/st

cc: Dr. B. R. Ashby
President-elect

Dr. John Buckman, UVA Med. Center

Dr. Stuart Ashman
Medical Director, T.P.I.

The David C. Wilson Neuropsychiatric Hospital - Charlottesville, Virginia 22901

~~advisory~~ response

April 25, 1978

National Commission on Confidentiality of Health Records
1211 Connecticut Avenue N. W.
Washington, D. C. 20036

RE: Michigan Medical Care Advisory Council

I have been appointed to an advisory group to the Michigan Medicaid agency. I learn that confidential medical information, including diagnosis and detail of treatment, is submitted, as to every recipient, to the agency, which stores it in a computer, which is available for authorized (and perhaps unauthorized) scrutiny.

While widely done, both in government circles and in private health insurance, I think it represents a deviation from ethical standards. I wonder if you could tell me how widespread the practice is, and whether there are programs that protect the individual patients' records from being duplicated at places other than the place of the treatment.

January 19, 1977

Ms. Natalie Davis Spingarn,
Executive Director
National Commission on Confidentiality
of Health Records, Inc.
1701 K Street, N.W., Suite 1205
Washington, D.C. 20006

Dear Ms. Spingarn:

Thank you for your letter of December 20, 1976 and the most interesting materials which accompanied the letter.

My feeling about your assignment is that it may be a well intentioned effort coming all too late.

The mood of physicians generally is resignation in the face of what seemd overwhelming social legislative and judicial decisions which have cut sharply into the patient/doctor relationship and have created a mood of hopelessness regarding the possibility of preventing patient's records from exposure.

Let me share an incident with you: At the meeting of the Huron Road Hospital Active Staff we considered several amendments to the bylaws. Among them was one which would regard all charts as belonging to the hospital and make all previous charts available to the new treating doctor for each successive admission. When I recommended that the patient be consulted regarding who should see his records and suggested that there were instances in my experience where patients emphatically did not want certain physicians to see their past records, I was received with some amazement by my colleagues.

The best I could was insist that the matter be referred to legal counsel so that the question of whether or not a patient had a "right" to limit who saw his medical records could be assessed.

The present generation of psychiatrists seem now to deal with the matter of protecting the patient by sharply limiting what is put in the record. This is now proceeding to a point where medical records are virtually useless for research and barely acceptable for patient management. Double and even triple records are being kept in some institutions. One for "show and tell" and the other as a working increment for the doctor's practice.

APRIL 25, 1978

NATIONAL COMMISSION ON
CONFIDENTIALITY OF HEALTH RECORDS
1211 CONN. AVE.
N.W.
WASHINGTON D.C. 20036

TO WHOM IT MAY CONCERN,

I RECENTLY HEARD ABOUT YOUR ORGANIZATION AND I AM
WONDERING IF YOU CAN ASSIST ME.

I HAVE HAD A PROBLEM WITH BREACH OF CONFIDENTIALITY OF MY
MEDICAL RECORDS IN A BOSTON HOSPITAL. ALTHOUGH, THE PERSON WHO
SOMEHOW GOT AHOOLD OF THE RECORDS HAS AN OUT OF COURT ORDER TO
STOP HARASSING ME, NOTHING HAS EVER BEEN DONE ABOUT THE RECORDS.
FRANKLY, IT HAS CAUSED ME GREAT PAIN AND WORRY ABOUT IT.

ALSO, SEVERAL FRIENDS OF MINE RECIEVED PHONE CALLS AND GIVEN
INFORMATION FROM THE RECORDS. THE INFORMATION WHICH OF COURSE,
THEY INFORMED ME ABOUT WAS ACCURATE AND COULD ONLY BE KNOWN BY A
PERSON WHO HAD ACCESS TO MY RECORDS.

I HAVE WANTED TO RESOLVE THIS MATTER FOR MONTHS. BUT FRANKLY I DON'T KNOW
WHAT TO DO AND THEREFORE, I LOOK FORWARD TO HEARING FROM YOU.

SINCERELY,

April 23, 1978

The National Commission on
Confidentiality of Health Records
1211 Connecticut Ave. N.W.
Washington, D.C. 20036

Dear Sir:

I am writing regarding a practice recently instituted at our local Thrift Drug Store, Shenandoah Valley Mall, Sharon Pa. Upon giving the pharmacist at this store a prescription from my family doctor to be filled I was approached by a clerk at the store with a form to be filled out with name, address, age and a list of all my health problems along with any medication I take for my ailments. The clerk was to print all my information on the form.

I refused to give them any information and they refused to fill my prescription.

They told me all the information I was to give to them was in confidence but was not told who had access to their records.

My ailments are my own business and I feel this is a wrong practice.

as well as possibly being illegal.
Please advise.

Sincerely yours,

P.S. This practice of the questionnaire was completely voluntary a month ago when I refused to fill it out then but within the last two weeks has become compulsory.

patient rights

11-21-70

Dear Commission,

Seven years ago I received in-patient care on a psych ward at one of California's University Hospitals. I was not committed by anyone and was not on a 72 hr. hold. Later I married and am now getting a divorce. My husband says he is going to use this information against me in his child custody fight. He also told me that his father, who is a lawyer, had obtained information about my hospitalization through his own sources.

I had assumed that even the fact I had been there was confidential. I am wondering how my father-in-law got his information, and if I can suppress this information in court. Any help you could give on this matter would be appreciated. (enc.)

April 29, 1978

Gentlemen:

This letter is in relationship to an article I read in the Denver Post, April 23, 1978 edition of Ann Landers. I am writing this letter regarding my specific problem.

Approximately 10 years ago, at the age of 19, I was committed to a mental hospital. I spent about 2 weeks there and never returned as an in-patient. I never returned to any other hospital on an in-patient basis, and the primary motivation of my conscious or unconscious decision was because of the disgusting and inhuman way I was treated. At any rate, over the last 10 years, I have counseled with various people of the psychology "profession" and have found most of the people lacking in basic respect for their clients, although I kept all appointments and was totally coherent at all meetings.

My question regarding this letter is that I would like copies of my (in-patient and out-patient) records at the mental hospital, but don't know how to obtain them. I have called two hospitals here in this geographic area, although I was not hospitalized here, but called to get some basic information on how I would go about getting permanent and complete copies of my files. Both times I was treated very rudely and told that I would probably have to go to court. My files are in the State of Ohio. Because of the geographic distance involved, I feel I will be taken advantage of by the profession.

Should I call the American Civil Liberties Union and have them to go court for me, or should I hire someone to obtain them for me? I have been told that while the information belongs to the hospital, the information IN the files is MINE and I have a legal right to them. However, I can't get a final answer because of conflicting answers.

My main reason for wanting my file is because of my fear of future discrimination in hiring, etc., and fear that my constitutional right of privacy will be invaded. I think I have a right to know what is my files. I'm not concerned with files outside the State of Ohio, but am concerned with those files in the State of Ohio. I have another question and that is, who has legal access to those files and is it required that when someone demands and obtains access to them, do I have the right to know who that person was, what date, and for what purpose they alleged they needed the file? Do I have the right to know who has seen my files in the past?

I am also very bitter over the fact that when I apply for jobs, etc., I must always have a fear that I will be asked questions such as above, which I honestly feel is noone's business. I run the risk of not being hired if I am stupid enough to tell the truth, and I run the risk of being fired if hired and later someone finds out the truth. I run the risk of being chronically unemployed for the rest of my life under circumstances beyond my control if I apply with certain entities. Perhaps you could tell me how to handle the problem in the future.

I feel strongly that you have a responsibility to demand legislation insisting that employers ^{etc} not ask such questions, just as gays may not be discriminated against in some places. Furthermore, I don't feel that the medical profession has done much of anything to help people in my situation and I would like to see a complete reversal in this profession's attitude and would like laws initiated as soon as possible to alleviate discrimination.

A self-addressed stamped envelope is enclosed for your convenience because I would like confidentiality in dealing with your organization. I would like to hear from you within 30 days. Thank you.


National Commission on Confidentiality of Health Records
1211 Connecticut Ave, NW
Washington, DC 20036

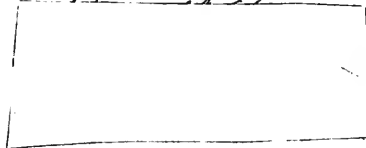
Gentlemen:

I recently read of your commission in an "Ann Landers" column in our local newspaper, and thought perhaps you might be able to give me some help or advice regarding a problem that I am having concerning my family's medical records.

In my work I have transferred several times and lived in a number of places around the country. Each time our doctors have transferred our medical records to our new doctor so that our medical records have been kept complete and up to date. The problem is that our last doctor refuses to send these records on to our present family doctor here in Omaha. What, if anything, can be done about this? I can see little or no value in his keeping these records. If anything, it could be detrimental to my family's present health care, as he is holding all of our previous records from all of our previous doctors, dating back as far as 1960.

I would appreciate hearing from you soon to see what can be done about this.

Sincerely, 



Dear Sir;

I am interested in what your commission intends to do about treatment for alcoholism. Recently, my driver's license renewal was held up simply because the state had obtained access to my health records via an insurance company's investigation.

Are you able to forecast the possibility of any health information being "privileged" when control of it leaves the original possessor's domain for some other than the original release purpose?

As a member of the U.S. Air Force, I understand that some things are better exposed than hidden; however, it seems like there is a lot of "McCarthy-like" witch hunting going on for no other purpose than to hurt the individual.

I would be interested in reading any material available on the protection of this area of personal privacy.

Thank you for your consideration. This letter is a direct result of your recent letter to Ann Landers.

Sincerely.

LIMITED TO
INTERNAL MEDICINE

BERNARD L. ALBERT, M.D., P.C.

150 WHITE PLAINS ROAD
TARRYTOWN, NEW YORK 10591

(914) 332-0090

August 4, 1977

Office of the President
Home Life Insurance Company
253 Broadway
New York, New York

Gentlemen:

This letter is written to advise you that an "agency employed by the Home Life Insurance Company to collect and transmit ... information" has been acting in a way which embarrasses the Home Life Insurance Company.

For 13 years I had been in the full time private practice of internal medicine in New York City. Almost a year ago I moved my office to Westchester County. I still hold a lease on my former office in New York City which is sub-leased to two groups of physicians. I visit that office at least once a week and occasionally see patients there by appointment. All records of patients I had seen in that office are retained in that office. That office incidentally is registered as a second office with the Bureau of Professional Licensing Services of the New York State Department of Education. I am still listed in the Bronx telephone directories but at my Westchester County address. I am a member of the Medical Society of the State of New York; I was a member of the Bronx County Medical Society but transferred my county society membership to the Westchester County Medical Society when I moved my office. The sub-tenants of this office hold all mail addressed to me and give it to me when I visit that office.

During the entire month of June I was told that numerous telephone calls were received at that office from a woman who wanted to speak to me but who would not give her name or address or telephone number and or stated her business and who always hung up before she could be given my current office telephone number. On a Friday afternoon towards the end of June I was in my former office when the receptionist for one of the physicians who now uses that office answered the telephone and told me that the same woman who had called so frequently was now on the telephone. I spoke to her and was told by her that she represented Equifax and asked me to relate over the telephone all confidential medical information in my possession regarding [redacted] she refused to tell me why she wanted this information or who she represented but instead said that she had an authorization

BERNARD L. ALBERT, MD. PC.

Office of the President
Home Life Insurance Company
253 Broadway
New York, New York

Page (2)

August 4, 1977

for release of this information and demanded that I give her this information. I refused to do so but suggested that she send the authorization to my current office address. In the next week I was, for lack of a better word, harrassed by this person who finally did state that she represented the Home Life Insurance Company. It reached a point that I contacted the Office of the Medical Director of the Home Life Insurance Company and was told I was acting properly in refusing to give confidential medical information over the telephone to a person I did not know without any authorization whatsoever from the patient. Then and only then did somebody personally bring to my office a photocopy of the "authorization and acknowledgement" signed by the patient. Once I received this authorization I then, when I was next at my former office, pulled the records and wrote out the "Underwriting Medical History Report - Privileged File". As inquiry was made about laboratory findings, rather than re-write probably illegibly the information, I left the "Report" with the laboratory reports from my file for photocopying where they were misplaced and apparently lost. For several days in their absence I received increasingly frequent and more anxious telephone calls from supervisors at Equifax demanding that I turn this report over. Each time they indicated the Home Life Insurance Company was going to take action such as refusing the policy and blaming the refusal on me. Finally one supervisor asked me if I had ever actually attended Equifax and request for any illness and when I said that I had seen him only once for a check-up and found him to be in good health, he suggested that if I had stated this when I was first contacted, Equifax could have completed its report and all this fuss would have been avoided. If I had only given this information to an unknown person without authorization, then it would have been easier.

Equifax personnel emphasized each time they called how important it was that the information be promptly obtained yet they wasted one month before locating me. I would think that an organization such as Equifax, which claims to be a "professional" in this business, would know that physicians do move. One of the supervisors told me that they have instructions from the Home Life Insurance

had

BERNARD L. ALBERT, MD. PC

Office of the President
Home Life Insurance Company
253 Broadway
New York, New York

Page (3)

August 4, 1977

Company to contact a "Dr. Albert of 1939 Grand Concourse, The Bronx, New York". He never inquired that this doctor might have moved. He was unaware that he could obtain a current address of a physician by contacting either the Bronx County Medical Society or the Medical Society of the State of New York or the Division of Professional Licensing Services of the Department of Education of the State of New York. He never thought that if he was looking for a Dr. Albert and there was no Dr. Albert in the Bronx but a Dr. Albert in Tarrytown listed in the Bronx telephone directory, he should call the Dr. Albert in Tarrytown to find out if he was the Dr. Albert in the Bronx. He was simply following his instructions from the Home Life Insurance Company to immediately get this information. In trying to "immediately" get this information, there was a six week delay, much harassment and annoyance, and use of what I feel an undesirable and I believe illegal approach in demanding that confidential medical information be given over the telephone without authorization.

I again suggest that you discuss this matter with your ~~Office of the Medical Director~~ who received telephone calls from me and whose secretary was actually asked to call up Equifax and request that they cease and desist from demanding medical confidential information without providing authorization in the name of the Home Life Insurance Company.

The final promise made by the supervisor of Equifax was that he was going to open a file on me with the inference that my non-cooperation will now be part of my credit record. I believe that as a matter of fairness, I should find out what if any action has been taken. Yes, a file should be opened but the file should state that I will not give out medical confidential information unless and until I have received an authorization from the patient to do so. It should also state that I desire not to be called and asked to violate a patient's confidence.

I also strongly suggest that you consider whether the conduct of Equifax is compatible with the image of the Home Life Insurance Company and whether they are really doing their job. For example, on July 18, 1977 the Allstate Insurance Company mailed a request for a medical report to my former office address with of course an authorization enclosed. This was picked up by me on July 22, 1977.

*and promptly
completed*

BERNARD L. ALBERT, MD. P.C.

Office of the President
Home Life Insurance Company
253 Broadway
New York, New York

Page (4)

August 4, 1977

I presumed that they received it on July 25, 1977, a week after it was requested. This report was received more promptly and at considerably less expense and was more accurate than any report obtained by telephone solicitation.

Also be aware that initially the people from Equifax refused to identify the organization requesting their services. The supervisors stated they were Home Life Insurance Company employees and did not identify their actual employer.

Thank you for your kind attention to this letter.

Sincerely,

BLA:jr

Bernard L. Albert, M.D., P.C.

July 6, 1977

National Commission on Confidentiality of Health Records, Inc.
 1211 Connecticut Avenue, N.W., Suite 504
 Washington, D.C. 20036

Gentlemen:

With regard to your quest for personal accounts, I have two:

Many corporations offer as a health benefit, a basic Blue Cross- Blue Shield plan and an additional major medical plan from another carrier. According to the personnel department, the department will offer its services as an intermediary in helping the employee obtain benefits from the major medical carrier. The services offered amount to the employee giving the personnel department the completely filled out claim form containing information from the patient and the physician, and the personnel department will then send the claim form to the major medical insurance carrier. In fact, this "service" is mandatory: the insurance carrier will only accept the claim form through the personnel department. This puts the claimant in the difficult position of having his own personnel department easily able to gather information on its own employee's health with its possible implications for invasion of privacy as well as implications with regard to future employability. One member of my family declined to apply for benefits and assumed the total costs of an otherwise covered illness rather than disclose to the personnel department a condition which might reflect upon job status.

This is not an isolated instance. I was formerly a government employee whose main office was three hundred miles away. Local physicians did not accept the Blue Cross-Blue Shield Plan from my main office, since they were unfamiliar with the form. My only recourse was to pay for my operation and submit the claim to my supervisor at work, through the mail (and through a secretary). My supervisor then submitted the claim to the personnel department who further processed the claim and submitted it to Blue Cross-Blue Shield. This enabled immediate co-workers, as well as others, to be aware of my vasectomy.

Fortunately for me, I am not ashamed of it (see? I even put it in this letter). However, my supervisor was decidedly against the operation from HIS religious point of view and this ~~could~~ could certainly have been a severe impediment for other co-workers of the same religious faith as my supervisor to have such an operation performed under similar circumstances.


I am aware of other situations not in my family due to an interesting fact: I am a ~~xxxx~~ registered pharmacist, although I do not practice pharmacy actively, but work in industry. Since my co-workers are aware of my profession and thus my alleged knowledge, I have had a number of confidences bestowed upon me. There are countless numbers of people, of whom I am personally aware, who have high blood pressure, mental conditions, and various physical conditions, who must (or feel they must) pay for conditions out of their own pocket, which conditions are covered by medical plans. However the fear of personnel using the information which they obtain through handling of major medical claims forms is a severe impediment to making claims. Further, the need to

pay for services ~~XXXXX~~ personally, rather than receive reimbursement, has caused some individuals to delay treatment for serious conditions when, in fact, the very establishment of medical insurance is designed to allow individuals to seek care that they cannot afford.

This history has resulted in another interesting situation. I have recently accepted a new position with a new employer. I chose my health benefits not on the merit of the benefit, but decided which package of benefits would allow my family and myself the greatest privacy with regard to my personnel department. I did, fortunately, find a benefit package which would afford me complete coverage and privacy, but did also reject other packages which may have served me better solely because of the necessity to have divulged my health care needs to the personnel department.

"There oughta be a law".

Just a brief statement in ~~XXXX~~ an area not of direct concern to you: There is now talk of prepaid LEGAL insurance. How would YOU like to divulge to your supervisor that you have been arrested and need your prepaid claim form in order to obtain proper counsel?

Sincerely, 

September 10, 1976

Robert L. Robinson, Executive Director
National Commission on the Confidentiality
of Health Records
1700 18th Street, N.W.
Washington, D.C. 20009

Dear Mr. Robinson:

Quite sometime ago, I read in one of our daily newspapers that your agency wanted to hear from former hospital patients who felt their medical records were shared with non-medical personnel against their wishes or without permission.

In a complete psychiatric report pertaining to my voluntary hospitalization at Hospital. , Illinois, was released to a the Dominican Sisters, Nashville, Tennessee. This was done without any consent on my part. I had applied to this Roman Catholic Sisterhood for entrance.

I was hospitalized at Little Company from for treatment of depression.

I had always been under the impression that such records were confidential. If I had known what was to follow, I would never have sought treatment. I can well understand why many people do not seek help for such problems. It is a disgrace that such records are open to any Tom, Dick or Harry for perusal.

If a simple Mother Superior can obtain such records without batting an eye, what chance does a person have with a large Corporation when seeking employment?

Very truly yours. .

*Meise, Cope and Coen**Attorneys at Law*

Suite 1800, Traders National Bank Building
 1125 Grand Avenue
 Kansas City, Missouri 64106
 (816) 221-6420

Clyde G. Meise
 W. Edward Coen, Jr.
 Robert O. Jester
 Mark A. Thornhill

James R. Cope
 Earl T. Hanson

April 24, 1978

National Commission on Confidentiality
 of Health Records
 1211 Connecticut Avenue, N.W.
 Washington, D.C. 20036

Gentlemen:

It is my understanding that you are involved with studies in regard to the confidentiality of individual health related records. I was recently contacted by a young lady in the Kansas City area who was extremely upset as a result of an experience she had with a local hospital and an LPN on its staff. This young lady was admitted to a unit in that hospital as a result of severe emotional depression which she was suffering. In the course of the hospitalization an LPN on the staff of the hospital gave all of the details of this young lady's admission to the facility to her roommate who happened to work at the same place as the patient and when the patient was released from the facility and returned to work she was immediately confronted with rumors, stares and other accusations which completely nullified any assistance she had attained while a patient in the local hospital.

This in my opinion is a truly unfortunate act on the behalf of this rather careless licensed practical nurse. I would like to be in a position to explain to this young lady what rights of confidentiality she has when a patient in a hospital and undergoing treatment for an emotional disorder. If you do provide the guidelines of confidentiality for the American Hospital Association, American Psychiatric Association and any Association which might represent licensed practical nurses I would certainly appreciate receiving that information.

Your consideration and cooperation will be more than appreciated.

Respectfully,


 Robert O. Jester

ROJ:jw

May 17, 1978

The National Commission on
Confidentiality of Health Records
1211 Connecticut Avenue, N. W.
Washington, D. C. 20036

Gentlemen:

I am writing to you because I think I need help with determining what information is in my health records. I have been mostly honest with employers in filling out their applications for employment and I have given them potentially damaging information about myself such as being hospitalized for a nervous breakdown.

I have been unemployed now for 26 months after my last employer dismissed me when I divulged this damaging information during a physical examination. I am worried that this information may be stored in a central data bank where employers generally have access to it. How can I find out if I am being hurt by this information?

Unfortunately, the state of Texas asks bluntly on their driver's license applications if I have ever had a nervous breakdown. Most employers in the state ask for driver's license numbers on their application for employment forms.

You can see that I am a prisoner of my past. Any information or help that you can give me about this matter will be gratefully acknowledged.

Sincerely yours,

Executive Director
 National Commission of
 Confidentiality of Health Records
 1211 Connecticut Avenue, N.W.
 Washington, D.C. 20036

Dear Executive Director,

I read your letter today in Ann Landers' column. I must apologize for the greeting of this letter, but she (rightfully so) did not print your name. Your letter was like a dream come true. I did not know where to direct my complaint as I was unaware of your organization.

I used to have a fantastic doctor here in Columbus. He was a member of a Family Practice Unit. During that time he performed satisfactory abdominal surgery on me. Unfortunately he has since gone to another town to open his own private practice. The nature of the operation was "female" and I'm not completely certain as to what he did. Since the surgery, and his departure, I have had more troubles.

A few weeks ago, I wanted to obtain my records from the Family Practice unit. They would not release them to me. They said in order to have them released I was required to

Page 2d
Executive Director
April 27, 1978

supply the name and address of my new physician, and they would forward them directly to him. I asked if I could see them if I wanted to and they said it would be up to my doctor; that a patient could not see their own records without permission. I checked with a lawyer and found they were within the law.

I feel I have, or should have, a perfect right to see my records at my own discretion. It is my body and no one should have the right to keep what is going on with it from me. Before surgery I signed a general release and I'd like to read for myself exactly what he did.

I feel certain that both my current physician and the one who did the surgery would cheerfully allow me to see my records should I request through channels. The point I'm trying to make is that I am a responsible adult and I don't need to be protected as a child or adolescent.

I am sure there is nothing earth shattering in my records, however, should there be, I should have the legal right to know. As I said before, it is my body.

Page #3
Executive Director
April 27, 1976

I wrote to my Congressman pertaining to this matter and he kindly informed me that there is no current legislation in the making to revise this type of situation.

Is there a possibility that anyone is going to instigate some sort of legislation concerning this matter? After all, most personal rights are already protected, i.e., "Freedom of Information" and "Privacy Act." This, in my opinion, is the same type of right that should be protected as well.

Any information you could forward, or tell me how to obtain, would be deeply appreciated.

Thank you very much for your time and allowing me to express my opinion.

Sincerely,



Mr. Robert L. Robinson, Executive Director
National Commission on the Confidentiality of Health Records
1700 18th St. N. W.
Washington, D. C. 20039

Dear Mr. Robinson,

I have no idea how private my health records are because I have no idea where my health records are.

I'm upset, and after having read the newspaper article about your group, I'm hoping you can help. This is the story: I am the mother of 5 children (12, 11, 9, 7 and 4). I teach school; my husband is a Civil Engineer. We have brought the children to a very fine pediatrician Dr. R. B. Mammal in our city. We have had a cordial relationship with our children's doctor and our bill

is paid. Last month, we read in the paper that Doctor was leaving town and we'd have until Aug. 31 to find a new doctor to whom records would be sent upon request. I followed those directions & found a new doctor and his office requested the records. Now comes the part that still has me amazed. On the day before Dr. Mamawale was to leave town, he accidentally called me (meant to call a Mrs. Carlow, he explained). While we were chatting, he matter-of-factly informed me that he would not release my records because they were his personal notes, he was not obliged to and since my 5 children were healthy, the whole procedure would be unnecessary. Then I told him I thought this was highly irregular and unfair, he became annoyed with my



(2)

lack of perception. Furthermore, I pointed out to him that I needed inoculation records for school. He said I should get them from the schools (an absurd suggestion, especially considering that my youngest is above the enter kindergarten). Then I expressed concern over ^{the fate of} my children's medical records; he explained curtly that they would be put in a "repository wherever that is!!" He knew I was very annoyed and ended the conversation. For 2 days I tried calling his office (number disconnected); going to the office (locked and a week later - sales writing (dropped a note in his mailbox; no reply). Then, to my surprise, I received a phone call from my new doctor's nurse saying that immunity records had been sent (along with

some notes someone made on the bottom of each child's sheet. But — not the complete records by any stretch of the imagination!!!

I need those records and have offered fifty for copies. Dr. Draney, I would like that basic statistics on my children (Perhaps, you consider that I should have kept better records myself, but I always knew Doctor had detailed records and not one person I've discussed this problem with has kept records as accurate as mine — so I feel less guilty about my meager records.) I explained these sentiments in a subsequent letter to Mrs. Mamawald (Doctor has gone in the Army). She called and told my son that the records had already been forwarded (concerning,



(5)

the shot records I've already mentioned.) In other words, they are not releasing the children's records as I've requested.

Now my questions to you: What about our rights? What about the rights of our children? Who will have access to these records? Where will the records be located? What if an emergency arises and it becomes necessary to investigate the children's medical history (as it stands now, they don't have a history). Can a doctor do this legally? What about invasion of privacy? Why won't he give us our records? Can he use our records for his own purposes? Are we at his mercy?

not I might point out that our case is not unique. Many other people, some friends

included, have been given the same run-around. Some have tried of this ridiculous game and have given up on the records - but I have not and don't intend to!

However, I'm baffled at the moment as to where to turn. Please help me solve this totally unnecessary problem so that I may relax, secure in the knowledge that complete copies of my children's medical records are in the hands of their need doctor as they properly should be.

I must commend you on your very important work. It is indeed startling to imagine that perfect strangers with God-knows-what motives would probably be better able than I to get hold of my children's medical records. Thank you.

Sincerely,

(Mrs.)

Medicaid Audit: Crisis in Confidentiality and the Patient-Psychiatrist Relationship

BY HARVEY J. SHWED, M.D., SEYMOUR F. KUVIN, M.D., AND RAVI K. BALIGA, M.D.

The authors describe their experience with a routine Medicaid audit and discuss the damage such a procedure can do to the trust between psychiatrists and patients, confidentiality, doctors' reputations, transference reactions, and patients' own emotional states. The authors point out that these crucial issues have broad implications because of the possibility of passage of national health insurance legislation.

CONFIDENTIALITY is undergoing intensive scrutiny because of the major upheaval in traditional concepts of the patient-doctor relationship in the past decade (1-3). Third-party insurers, whether private or government, armed with computers and data banks, have seemingly insatiable appetites for detailed information about what transpires between doctor and patient in order, they say, to justify the benefits they pay and to be assured that competent medical service has been rendered (4-9). What are the boundaries between the

right to know and the doctor's time-honored pledge to patients of confidentiality?

Nowhere is confidentiality more basic to a discipline than in psychiatry and psychotherapy. Our experience suggests the possibilities for destruction of this patient-psychiatrist trust in a routine Medicaid audit of a psychiatrist's practice. (Medicaid is the federal-state program that pays for the health care of 28 million low-income Americans who meet eligibility guidelines for participation.)

MEDICAID AUDIT PROCEDURE

In New Jersey, a Medicaid audit is an investigation of a physician and his or her practice. It is for the most part a routine check of doctors who treat significant numbers of Medicaid-sponsored patients. Medicaid staff limitations prevent the staff from scrutinizing all doctors who see Medicaid patients. They therefore give priority attention to doctors who see a large number of Medicaid patients or whose practice has raised the suspicion of fraud or abuse. We were audited because Medicaid patients comprise approximately 10%-15% of our private group psychiatric practice, which is located in a medical school-affiliated teaching hospital in Newark, N.J.

The Medicaid audit as typified by our experience includes the following:

1. The psychiatrist's office is informed of the impending audit and a mutually convenient appointment

Received Oct. 4, 1977; accepted Jan. 9, 1978.

Drs. Shwed and Kuvin are Co-Directors, and Dr. Baliga is on the staff, Psychiatric Institute, Saint Michael's Medical Center, 268 High St., Newark, N.J. 07102. Drs. Shwed and Kuvin are also Clinical Assistant Professors, and Dr. Baliga is Clinical Instructor, Department of Psychiatry, New Jersey Medical School of the College of Medicine and Dentistry of New Jersey. Send reprint requests to Dr. Shwed.

is made. The doctor is told that 25 or 30 patient charts will be reviewed the day of the audit and that preselected patients will also be interviewed by the audit team either before or after the formal visit to the psychiatrist's office. The identity of the patients is not revealed until the day of the audit. Members of the audit team who interview physicians in the field are usually not physicians.

2. The team interviews the psychiatrists and asks about such items as Board certification or eligibility, medical school affiliations, and names of other physicians and staff members within the practice.

3. The team asks for the charts of the preselected patients.

4. The team views and reproduces the charts. This procedure is especially important to them because a Medicaid physician at the central office ultimately reviews these patient records. In cases where a doctor is suspected of fraud or abuse, such charts and records serve as evidence for the Attorney General's office.

5. The team also reviews office bookkeeping procedures. Because New Jersey Medicaid will not reimburse psychiatrists for unkept appointments, the audit team searches for deviations from this standard when examining a psychiatrist's records. The audit team asks to examine the doctor's appointment books, presumably to assess the time the psychiatrist devotes to each patient.

6. The auditors, according to what our patients have told us, ask questions relating to a) quality of care patients feel they have received, b) how they like their doctor, c) how much time the psychiatrist spends with them, d) whether they were "prepped" for the interview by their doctor, and e) if they have any complaints about the doctor or his or her practice.

7. The team collects any information doctors offer as documentation of the kind of service rendered to their Medicaid patients. We supplied to the audit team copies of an introductory and orientation brochure we give each new Medicaid patient. The brochure explains our practice policies, provides emergency numbers to call when our office is closed, and indicates our "on call" availability. It also attempts to deal with the issue of unkept appointments, a serious problem in a psychiatric practice and, unfortunately, a characteristic pattern for many Medicaid-sponsored patients. We also supplied our weekly statistics of unkept Medicaid appointments to the audit team.

To document our contention that Medicaid patients receive extraordinary amounts of extra session service and time, we asked every member of our staff to keep a log for one month of the time and effort devoted to our Medicaid patients other than face-to-face psychotherapy sessions.

THE PSYCHIATRIST-PATIENT TRUST

It is difficult for us to conceive of meaningful psychotherapy taking place without implicit and explicit

guarantees to the patient that confidentiality will be maintained (10, 11). Under the best of circumstances, patients enter psychotherapy with varying degrees of suspiciousness, resistance, and mistrust, based on their earlier life experiences.

Guarantees of confidentiality are crucial to the special trust between patient and psychiatrist that permits the patient to share increasingly intimate and difficult material with the therapist. For the overly sensitive or frankly paranoid patient any hint that confidentiality has been violated will destroy the therapeutic endeavor. So fragile and yet important to psychotherapy is the concept of confidentiality that, in our opinion, merely the idea that someone might have access to intimate material precludes meaningful psychotherapy from taking place.

On the first day of contact with the psychiatrist, the Medicaid patient signs a form permitting the psychiatrist to receive reimbursement for his or her services, which also gives Medicaid permission to examine and request any and all charts.

Patient Certification. Authorization to release information, and payment request. I certify that the service(s) covered by this claim has been received, and I request that payment be made on my behalf. I authorize any holder of medical or other information about me to release to the Division of Medical Assistance and Health Services or its authorized agents any information needed for this or a related claim.

It is our belief that the nature of the Medicaid form brings greater pressure to bear on the Medicaid patient than on other patients. Middle-class patients do not have to sign such a form, and, in fact, many of them decide not to sign any insurance form because of the issue of confidentiality. Regrettably, they end up paying for psychotherapy on their own.

Medicaid's "Right to Know"

In New Jersey, 600,000 residents receive Medicaid funds, and the state and federal governments spent \$429,577,145 for their health care in 1976. Across the nation, 28 million Americans depend on Medicaid for their health care, at a total cost of \$14.7 billion. A program encompassing so many people and such large sums of public money may justly argue that it has not only a right but a responsibility to American citizens to monitor the medical care that they pay for. The executive and legislative branches of government expect it and the general public, whose tax dollars pay for the program, demands it.

Violations of Confidentiality

The act of reading psychiatric patient records by the staff of a geographically distant bureaucratic agency makes a sham of any pretense of confidentiality between a psychiatrist and his or her Medicaid patients. The Medicaid team who conducted our audit were not physicians. They were polite, deferential, and tactful

as they went about their business; nevertheless we shared a deep feeling of having been violated and having in turn betrayed our Medicaid patients.

Our sense of outrage was intensified by the knowledge that the selected patient charts were to be copied and transferred to central Medicaid offices in Trenton where they would be reviewed by the "psychiatric consultant." What would ultimately happen to these copies of our patient records was not made clear.

Medicaid's own policy of guaranteeing confidentiality and promising serious penalties to any staff member found guilty of violating such confidentiality is inadequate for the psychiatrist and his or her patient. In our opinion, merely the act of sharing psychiatric material with "benign" strangers is detrimental to the patient-doctor relationship.

In addition to the symbolic impact that Medicaid's "right to know" has upon the therapeutic alliance, there are more realistic and practical issues. We are less concerned with nefarious deeds perpetrated by "Big Brother" governmental agencies (although the Watergate-related Daniel Ellsberg case comes to mind) than with the inadvertent foul-ups that seem likely to occur when any large bureaucratic organization has confidential data at its disposal. The recent disclosure that names of 48,000 New York State women who had undergone abortions had not been deleted from data transmitted to the National Institutes of Health for a research project is a case in point (12).

PATIENT-PSYCHIATRIST RELATIONSHIPS

Psychiatrist and Staff Anxieties

An audit or examination, no matter how routine and from whatever the source, evokes anxiety in the psychiatrist and his or her staff. In an age of increasing government involvement (e.g., potential national health insurance, PSROs, and mental health advocacy), psychiatrists and their physician colleagues should be prepared for the onslaught of those carrying "right to know" passes.

The nightmare of every ethical physician is that a government investigating team, which consciously or unconsciously must justify its existence, will be too rigid and literal in interpreting rules or regulations and will fault doctors for not "dotting their i's or crossing their t's." In the case where an investigation leads to an actual indictment, ultimate acquittal is little consolation to the doctor who in the meantime has suffered irreparable damage to his or her professional reputation, days and months of emotional stress, and income lost from his practice and from legal fees.

The Effect of Patient Interviews

One of the charges leveled against a doctor in our state who was ultimately indicted for Medicaid abuse was that he attempted to "prep" his patients for their interview with the team. The Medicaid team, naive

about psychotherapy issues and techniques, might therefore view any pre-interview discussions with our patients as an attempt to influence the patient's honest and frank responses to their questions, so when we were informed of the Medicaid audit, we felt constrained not to discuss it with our Medicaid patients. This violates a basic tenet of psychotherapy: that anything and everything relevant to the patient's psychotherapy can and should be discussed.

One psychiatrist, not in our group, told us that after a Medicaid audit interview patients called to warn the therapist that he was "in trouble." No matter how benign the investigation may be or how nonpejoratively it may be presented to the patient, the therapeutic relationship has been injured and, by innuendo, the psychiatrist's reputation has been harmed.

Furthermore, the type, intensity, and stage of transference reactions between the patient and psychiatrist may be interfered with by the audit interview. Likewise, transference may significantly distort the patient's replies to the investigator's questions; patients' responses may be unrealistically glowing and warm when positive or even erotic transference is occurring and unfairly damaging if the patient is working through issues of negative transference at the time of the audit.

The selection of patients who will be interviewed by the audit team does not, to our knowledge, consider the patient's psychological ability to take part in the interview or how the dialogue might be emotionally harmful to the patient. What is the effect of the audit interview on the patient who is fragile and overly anxious, paranoid, withdrawn, reclusive, passive-aggressive, or sociopathic? How do these characteristics influence and distort the replies that are given, especially to a nonmedical, nonpsychiatric investigator? What is the ultimate effect on the nature and future of the therapy and the patient-psychiatrist relationship?

COMMENT

As America moves closer to a national health insurance program, health planners, politicians, and government officials are gaining experience from the current health payment program for the 28 million Medicaid-sponsored citizens in the United States. The majority of psychiatrists in private practice who do not see Medicaid patients will face similar issues if and when they are blanketed into a national health insurance program serving a more universal population.

The overriding philosophical issue, with many diverse practical ramifications, is whether a government-administered health program, which spends large sums of public tax money and insists that it has the right to know in order to monitor quality of care and insure fiscal integrity, can accommodate the need to maintain a meaningful patient-psychiatrist relationship and confidentiality.

The task of dealing with and reconciling these conflicting needs is awesome.

REFERENCES

1. American Psychiatric Association: Position statement on confidentiality and privilege with special reference to psychiatric patients. *Am J Psychiatry* 124:1015-1016, 1968
2. American Psychiatric Association: Position statement on the need for preserving confidentiality of medical records in any national health care system. *Am J Psychiatry* 128:1349, 1972
3. Gurevitz H, Tarasoff: protective privilege versus public peril. *Am J Psychiatry* 134:289-292, 1977
4. Noll JO, Hanlon MJ: Patient privacy and confidentiality at mental health centers. *Am J Psychiatry* 133:1286-1289, 1976
5. Westin AF: Computers, Health Records, and Citizen Rights. Monograph 157. Washington, DC, US Department of Commerce, National Bureau of Standards, 1976
6. Grossman M: Insurance reports as a threat to confidentiality. *Am J Psychiatry* 128:64-68, 1971
7. Bush V: New data battle: state's need to know vs. patient's privacy. *Mod Health Care* 3:60-61, 1975
8. Baldwin JA, Leff J, Wing JK: Confidentiality of psychiatric data in medical information systems. *Br J Psychiatry* 128:417-427, 1976
9. Schuchman H: Editorial: on confidentiality of health records. *Am J Orthopsychiatry* 45:732-733, 1975
10. Dubey J: Confidentiality as a requirement of the therapist: technical necessities for absolute privilege in psychotherapy. *Am J Psychiatry* 131:1093-1096, 1974
11. Closson WG Jr, Hall RA, Mason BS: Confidentiality in psychiatry and psychotherapy. *California Medicine* 113:12-15, 1970
12. Abortion study with names. *New York Times*, May 15, 1977, section 4

[Whereupon, at 1:55 p.m., the subcommittee adjourned, to reconvene at 10 a.m., Monday, April 9, 1979.]

PRIVACY OF MEDICAL RECORDS

MONDAY, APRIL 9, 1979

HOUSE OF REPRESENTATIVES,
GOVERNMENT INFORMATION
AND INDIVIDUAL RIGHTS SUBCOMMITTEE
OF THE COMMITTEE ON GOVERNMENT OPERATIONS,
Washington, D.C.

The subcommittee met, pursuant to recess, at 10:05 a.m., in room 2203, Rayburn House Office Building, Hon. Robert F. Drinan (acting chairman of the subcommittee) presiding.

Present: Representatives Robert F. Drinan, Ted Weiss, Thomas N. Kindness, M. Caldwell Butler, and John N. Erlenborn.

Also present: Timothy Ingram, staff director; Robert Gellman, professional staff member; Euphon Metzger, secretary; and Thomas Morr, minority professional staff, Committee on Government Operations.

Mr. DRINAN. The subcommittee will come to order.

In the absence of the distinguished chairman of the subcommittee, Congressman Richardson Preyer, I will preside.

Last Wednesday this subcommittee began hearings on privacy of medical records. We began with a presentation of the administration's general approach to privacy issues and received a statement explaining the medical records provision of the administration's proposal.

The chairman of the National Commission on Confidentiality of Health Records also appeared before the subcommittee.

Today we continue to examine the legislative proposals, H.R. 2979 and H.R. 3444, both of which would protect the confidentiality of medical records.

Our first witness this morning is Ms. Jane Rogers, director of legislative affairs, American Medical Record Association. She is accompanied by Ms. Lorraine Volz, Thomas Jefferson Hospital in Philadelphia.

We welcome you both and invite you to proceed with your statement.

I will announce the other witnesses now and will come back to them. Our second witness will be Dr. Jerome Beigler, chairman of the American Psychiatric Association Committee on Confidentiality.

Thank you for bringing us your statement on this important issue, Dr. Beigler. We will get to you soon.

Our last witness will be Dr. Leon Gordis, who is representing the Society for Epidemiological Research, American Association of Medical Colleges.

We are very happy to have you here, Ms. Rogers. We have your statement. Without objection, it will be made part of the record. You may proceed in the way that you desire.

STATEMENT OF JANE ROGERS, DIRECTOR OF LEGISLATIVE AFFAIRS, AMERICAN MEDICAL RECORD ASSOCIATION; ACCOMPANIED BY LORRAINE VOLZ, DIRECTOR, MEDICAL RECORD DEPARTMENT, THOMAS JEFFERSON UNIVERSITY HOSPITAL, PHILADELPHIA, PA.

Ms. ROGERS. Thank you very much.

We would like to submit our written testimony and we will summarize this testimony here today.

I represent the American Medical Record Association, an organization representing more than 22,000 registered record administrators, accredited record technicians, and others interested in medical records and health data. The primary purpose of the association is to promote comprehensive health record services for the welfare of the public.

I appreciate the opportunity afforded by this subcommittee to provide information about confidentiality and medical record practices and problems as perceived by the American Medical Record Association and profession.

Historically, the primary purpose of the medical record has been the care of the patient—to document the cause of health care and to provide a medium of communication among health care professionals.

In recent years, however, our society has seen changes in the delivery, payment, and accountability mechanisms of the health care system, which have subjected health facilities and medical record departments, in particular, to staggering demands for medical information. You may now assume that medical records are used only for patient care, but just listen to the potential secondary users: (1) payers for health services, both private and Government insurance plans and programs; (2) public health agencies; (3) medical and social researchers; (4) rehabilitation and social welfare programs; (5) employers; (6) insurance companies; (7) Government agencies; (8) educational institutions; (9) judicial processes; (10) law enforcement and investigation; (11) credit investigation agencies; and (12) accrediting, licensing, and certifying agencies.

A typical hospital medical record includes the patient's name, address, age, next of kin, and other identifying information. The medical history includes the chief complaint; details of present illness; past medical, psychiatric, social, and family histories; treatments, and other sorts of things.

The physical examination record contains positive and negative findings of a comprehensive current physical assessment and a preliminary diagnosis.

The record contains findings of diagnostic tests administered, consultations sought and rendered, all orders for medications and treatments, and there is a comprehensive summary written at the time of discharge.

The amount of detail recorded in the medical record may be affected by the knowledge on the part of the patient, members of

the family, or the physician and other health care practitioners about possible uses of the record.

Patients who are aware that the information in the record may be available to third party payers, attorneys, employers, life insurance companies, or others may withhold certain information that he believes can be used against him or that he considers to be of such a personal nature that its disclosure might be embarrassing.

Similarly, members of the patient's family may not wish to make full disclosure for the same reasons. This situation is of growing concern to physicians who fear that the demands for medical information for purposes other than care of the patient has resulted in concealment of important information having direct bearing on their ability to diagnose and treat the patient.

Cases of abuse resulting from access to medical records and medical information are well documented. Perhaps the best known criminal cases are the *Ellsberg* case and the recent *Denver* case, in which private investigative firms hired by insurance companies posed as medical professionals and obtained medical records under false pretenses from hospitals.

Other sample cases of misuse or mishandling of medical information includes transfer of diagnoses from the insurance company to patients' employers, transfer of information on a husband or wife who has been a patient via the insurance company and/or employer, linkage of medical with nonmedical computer files in the name of research, use of medical information in denying insurance, employment, and so on.

Traditionally, it has not been the practice of health care providers or institutions to provide the patient access to the medical record itself. In the last few years some 14 States have made statutory provisions for such access. It has been the practice to give verbal information about facts the patient should have or to provide certain summary data to the patient, and these practices seem likely to increase with the growing recognition of the individual's right to know.

The American Medical Record Association supports the right of the patient to have access to his medical record. In an era when the medical record is widely reviewed we believe the patient, too, deserves this right and that such a right is necessary for the patient to be truly informed when he signs an authorization for release of the medical record. AMRA's model policy on patient access reads:

Subject only to specific contraindications by the attending physician and to any legal constraints such as those governing minors and those adjudicated as incompetent, a patient may have access to his own health record for review upon written request with reasonable notice. A patient may have access to records of his care after discharge and completion of the health record. Photocopies of health records will be provided on written request by the patient and payment of a reasonable fee.

The majority of releases of medical records are made only after the patient has signed an authorization for release of such information. However, a major problem in the confidentiality question is the format and methodology of such authorizations or consents signed by the patient. There are three types of consents which pose a problem: The blanket consent, the prospective consent, and the perpetual consent.

First, in blanket consent patients or guardians are asked to sign releases which allow facilities to disseminate "any and all" identifiable information to whomever is offering a benefit or service to the patient. The patient is not himself "informed" as to the full extent of the record's content, which segments of it will be open to third party access, or what will happen to the information once it is in the third party's possession. Blanket consent does not serve to instill a sense of responsibility in the collectors, storers, and users of patient data.

Second, difficulty arises from the common third party practice of requesting prospective consent, or consent of release of information prior to treatment. This means that the patient is consenting to the dissemination of that which is not yet collected, a practice which precludes any intelligent decisionmaking on the part of the patient.

Third, most insurance companies request a form of consent which could be construed as perpetual consent, since there is no attendant time limit set for validity of the consent. With other requestors, health care institutions vary in the time limits within which they accept patient consent as current. In some cases health care institutions are adopting more stringent limits, but there is no uniformity of policy in this area.

The most frequent disclosure of medical record information is to third party payers: Blue Cross, Blue Shield, commercial insurance carriers, and Federal and State Governments, whether directly or through fiscal intermediaries, for reimbursement or claims purposes.

The amount of information provided is usually determined in relation to the purpose and to the scope of authorization. The demands of third party payers were, in the past, reasonably limited. Increasingly during the past several years, demands for more extensive documentation in connection with claims processing have expanded to include copies of discharge summaries or, more and more frequently especially for medicare or medicaid reimbursement, photocopies of the entire medical record. This presents a costly and time-consuming demand, and the extensive disclosure involved is disturbing to medical record practitioners in light of their ethical responsibilities.

We believe that the practice of copying entire medical records for review outside hospital premises is a practice largely for the "convenience" of fiscal intermediaries, insurance companies, PSRO's, et cetera. AMRA has voiced its opposition to this practice to no avail.

The American Medical Record Association's position statement on confidentiality includes the following model policy on authorizations:

All information contained in the health record is confidential and the release of information will be closely controlled. A properly completed and signed authorization is required for release of all health information except:

- A. As required by law;
- B. For release to another health care provider currently involved in the care of the patient;
- C. For medical care evaluation;
- D. For research and education.

In keeping with the tenet of informed consent, a properly completed and signed authorization to release patient information shall include at least the following data:

- A. Name of institution that is to release the information;
- B. Name of individual or institution that is to receive the information;
- C. Patient's Full name, address, and date of birth;
- D. Purpose or need for information;
- E. Extent or nature of information to be released, including inclusive dates of treatment—Note: An authorization specifying "any and all information. . ." shall not be honored;
- F. Specific date extent, or condition upon which consent will expire unless revoked earlier;
- G. Statement that consent can be revoked but not retroactive to the release of information made in good faith;
- H. Date that consent is signed—Note: date of signature must be later than the dates of information to be released;
- I. Signature of patient or legal representative.

This ends the AMRA statement on authorizations.

We believe that legislation which provides strict provisions for authorizations will be a great asset to limiting disclosure of information, especially copying and disseminating entire copies of medical records. We caution Congress, however, not to place the sole provision for proper authorization in a medical record privacy act. Responsibility should also be placed on the insurance and law enforcement industries through legislation pertaining to those industries. Such responsibility includes the medicare/medicaid and other Federal insurance programs as well as private carriers.

Release of medical records without a signed authorization is considered a legitimate practice under several instances: Release to health employees and consultants caring for the patient, for health research, audits and evaluations, public health and safety, law enforcement, judicial and administrative proceedings, and per subpoena, summons, or search warrants.

Any legislation should state explicit circumstances under which medical records can be obtained without authorization and should provide safeguards to prevent direct or indirect identification of patients or further disclosure from those receiving records.

To meet the demands and needs for information, health care facilities and recipients of information have turned to computerized systems.

Infinite storage capacity and linkage ability between computerized technologies has dealt the greatest blow to confidentiality. Massive nationwide data systems are operated by Blue Cross/Blue Shield, Medicare, DHEW, PSRO's, private insurance carriers, and insurance service firms such as the Medical Information Bureau and Equifax. These systems not only have the capacity to link data but are active in this endeavor.

Perhaps the most frightening aspect of computerization in health today is activity supported by Congress through passage of Public Law 95-142, Medicare/Medicaid Antifraud and Abuse Amendments of 1977, section 19, and under the jurisdiction of the Department of Health, Education, and Welfare's Health Care Financing Administration.

DHEW will soon issue proposed regulations which call for the collection of a uniform hospital discharge data set which involves patient and provider identities, diagnoses, and other specific information. The UHDDS will be collected and processed by regional processors. Identifiable data will be linked to billing data and stored in a national data bank in the DHEW. Data will be distrib-

uted to PSRO's, HSA's, and other Federal departments. The national health computer bank which we were told would never be created is here. There is no reason to believe that at some future date this health data will not be linked to FBI, CIA, IRS, credit, insurance, and other computers. AMRA has voiced strong opposition to DHEW plans for data collection and we await proposed regulations.

Any national health insurance program is likely to expand reporting requirements and centralize the information collected in data banks.

Legislation created the authority for current computer activity. Any legislation on data security must first put limits on data collected and place stringent restrictions on release and linkage.

The medical record practitioners, health providers, and patients are in a serious dilemma over confidentiality. The dilemma of the medical record profession centers on how to fulfill the obligations to provide needed information to serve the patient, provider, and the community while protecting the patient. The dilemma for the health provider is confidentiality versus payment for services on a timely basis to assure cash flow. The dilemma for the patient is confidentiality versus insurance, employment, credit, and other services. In reality, the question comes down to confidentiality versus money.

In summary, the American Medical Record Association strongly suggests voluntary and legislative efforts: To provide patient access to medical records with proper restrictions; to assure the patient full knowledge of and control over dissemination of his private information through strict authorization for release of information; to control redisclosure by secondary recipients and users of medical information; and to control linkage of computerized health information systems.

In conclusion, I quote from "Computers, Health Records, and Citizens Rights," a study conducted under the Institute for Computer Sciences of the National Bureau of Standards, by Alan Westin:

As American society redefines and reorganizes its health care system in the coming decade, it will have to make increased use of computer technology to manage the rivers of data that will be generated. . . . If the question is not whether but how such technology will be used in health care, American society has one nonnegotiable condition for this process. Basic citizen rights cannot be made a casualty of technology-assisted health systems. To do so would be to betray the tradition of Hippocrates, and ultimately to dehumanize health care itself.

This ends our summary.

We would like to thank the subcommittee staff for their assistance in our preparation of testimony and the questions that we gave to the subcommittee.

Mr. DRINAN. Thank you very much for an excellent statement and a very comprehensive one.

Also, I want to commend you and your association upon the professional standards which you are disseminating and developing for 22,000 registered record administrators.

You state the case very well in your summary, it seems to me, but may I ask just a couple questions?

Ms. ROGERS. Certainly.

Mr. DRINAN. Is it possible that the American Medical Record Association, along with everybody else in the health field, could develop adequate voluntary efforts in this area so that legislative guidelines would not be necessary—at least at the Federal level but perhaps with State guidelines?

Ms. VOLZ. Mr. Drinan, I would be inclined to say that it would be better to have them developed at the Federal level because you would see such a tremendous variety at the State level. There would be no consistency among them.

Mr. DRINAN. I take it you want these Federal guidelines or some form of the bill that the chairman of this subcommittee proposed to the administration?

Ms. VOLZ. Yes. That would be very helpful.

Mr. DRINAN. Would you expand just a bit, Ms. Rogers, on what you stated on pages 18 and 19? You say there is no reason to believe that the health data will not get into the hands of the FBI, the CIA, and the IRS. Isn't there some legislative way to prevent that from happening?

Ms. ROGERS. I am sure that if this national health data bank is created, which we believe it will be, then that perhaps would be the only way to prevent a future linkage of the systems.

I might give you an example. We will present this case for the record after the hearing today. There is a State in which there is a State law that requires that all abortion cases be submitted to the State agency within 48 hours of the abortion. In the name of research it has been documented that the names of these patients were put into a computer file and that there was cross reference between the driver's license and the State tax services. This is a very good example of what can happen to medical information that is collected for supposedly legitimate reasons and how it can get into the computer linkage setup.

For this reason, we see no reason that there would not be linkage to other Federal computer systems in the future. I think legislation would have to be mandated to prevent this.

Mr. DRINAN. I welcome your comments. I yield at this time to the gentleman from Virginia, Mr. Butler.

Mr. BUTLER. Thank you, Mr. Chairman. I would prefer to defer to Mr. Erlenborn.

Mr. DRINAN. I would be happy to yield to the gentleman from Illinois, Mr. Erlenborn.

Mr. ERLNBORN. Thank you very much, Mr. Chairman.

Ms. Rogers, I would like to follow up on a question that Father Drinan asked about the tie-in on this Department of HEW computer bank of information to other parts of the Federal Government, the insurance industry, and so forth.

Are you familiar with the so-called Privacy Act?

Ms. ROGERS. Yes.

Mr. ERLNBORN. You are aware that would prohibit such tie-ins or other uses of the information other than those published in the Federal Register?

Ms. ROGERS. Yes.

Mr. ERLNBORN. Don't you think that is a safeguard already existing?

Ms. ROGERS. There is some safeguard in that. However, I have some question by virtue of the statutory authority under which HEW is creating the data bank, which is the Fraud and Abuse Act. I would have some question as to whether or not there are loopholes in this process whereby this information could be linked in spite of the Privacy Act.

Mr. ERLBORN. You are aware that under the Privacy Act whatever use is contemplated as being made of this information on a regular basis must be published in the Federal Register so that you and the general public would know what uses are being made of the information. Then if you object, you would have an opportunity to object and come to the Congress or go to HEW to try to prohibit them from making that ordinary and customary use.

Ms. ROGERS. Yes.

Mr. ERLBORN. Don't you think that is a safeguard that now exists?

Ms. VOLZ. I would think we as a professional organization that reads the Federal Register might be aware of that, but many individual patients would not. On that basis, I think there could be possible abuse.

Mr. ERLBORN. Of course there are 220 million people in the United States who are not aware of what is in the Federal Register. It is not the best seller really. It has wide dissemination. That is the reason for the existence of organizations such as yours, is it not?

Ms. VOLZ. Yes.

Mr. ERLBORN. The reason is to maintain vigilance?

Ms. VOLZ. Education of the public is one of the problems. Many abuses go on because of the ignorance of the public. That is the reason for our concern.

Mr. ERLBORN. I am extremely pleased to have been associated personally with the passage of the Privacy Act. I think the mere fact that we have required the Federal agencies to publish and identify every record system that they maintain was a great step forward. We all know what is being done now. Some of the agencies found out for the first time themselves what they were doing because they were forced to catalog their systems, describe them, and publish them.

Second, to publish the customary use of those records lets us all know what the ground rules are. This has been a great step forward. It gives us a great deal of protection.

Relative to Federal legislation, you made the comment that it would be desirable to have uniform rules. Would you make the same judgment when it came to licensing of dentists, physicians, nurses, hairdressers, automobile drivers, registration of automobiles, and a myriad of other licensing and registrations that are done at the State level?

Ms. VOLZ. There are so many ramifications to all those. I would think regional differences would have to be taken into consideration. I would prefer not to answer that question without a little bit more preparation.

However, the reason for saying that Federal legislation would be very helpful is based on looking at the State regulations, those

State laws presently in effect. There is a tremendous variance among them.

The one in the State with which I am familiar, Pennsylvania, has two sentences which give the patients access. It offers no guidelines to those regulations. It has a simple statement saying that this is the patient's right to have it in a completely unrelated place. It makes it difficult for interpretation.

Other State laws are less than that, and some are much more specific than that. They do not all address the basic issues that the proposed legislation does. Therefore, in order to assure that the good things in the proposed legislation are carried through uniformly is my reason for saying Federal legislation would be helpful.

Mr. ERLNBORN. I will just make this personal comment. I have been disturbed in recent years by the volume of people turning to the Federal Government because it is so much easier to get a job done in one place than in 50 different places. If that had been the philosophy 50 or 100 years ago, we never would have had the types of regulations that I have just described—automobiles, doctors, dentists, hairdressers, and so forth. Those never would have developed in the way that they have.

That philosophy rather reminds me of the labor union organizer that I ran into in my law practice who went to the owner of a business and said, "I want you to sign a contract recognizing our union as the sole bargaining agent of your employees."

The employer said, "Well, if a majority of my employees want you to be their bargaining agent, that is OK with me but you had better go talk to them."

His answer was, "oh, no, it is so much easier to get you to sign this. All I have to do is convince one person rather than a couple hundred people out there in your plant."

It is easier, but I question whether it is the right way to go about it.

Thank you very much.

Mr. DRINAN. I yield to the gentleman from Virginia, Mr. Butler.

Mr. BUTLER. Than you, Mr. Chairman.

I have appreciated the testimony of the witnesses. I have read it with some interest.

I guess I always want some horror stories for the record. Do you have a few you might want to give us at this moment?

Ms. ROGERS. I think we both probably have a few. I could start off with this:

One area of concern in which there have been some abuses has been the area involving the health facility, the insurance company, and the employer in the transfer of information on a legitimate basis to the insurance company. There are cases cited whereby medical information, including the diagnostic information, on patients has been transferred by signature of the patient to the insurance company. Where an employer would hold a group health policy, the employer then obtains information from the insurance company on the employee.

There are two cases that I could cite where there is abuse of confidentiality. One involves a husband or wife who is the employee of the company who receives information on the entire family, the nonemployed husband or wife, through the insurance company

by the employer. In essence this is the husband or wife obtaining information about the other without their signed permission.

Mr. BUTLER. I can see how that would be frightening.

Ms. ROGERS. Another is a psychiatric case that was stated. A woman went in for a psychological checkup and did improve and return to work. Through her employer she received a piece of paper in which she was diagnosed as a schizophrenic. The knowledge of the diagnosis itself, plus the knowledge that the employer and people in the employ of her employer knew this, provided a setback for her.

This, of course, is a particular area of sensitivity in the psychological realm where very often the psychiatrist will not divulge the full contents of the record to the patient. That is one area that is particularly sensitive. For a patient to get this information through the insurance field and the employer is particularly a bad situation.

Mr. BUTLER. Would you characterize abuses as widespread? How big a problem is this? These are the horror stories. How big a problem is this percentagewise?

Ms. VOLZ. It would be hard to give you actual statistics. They do exist. In what proportion to the whole it is difficult to know. Not everybody knows what the aggregate information is. I would not even want to venture a guess as to what the percentage would be, but I think it is very definitely there.

Mr. BUTLER. Thank you.

Mr. DRINAN. I am happy to yield to the gentleman from Ohio, Mr. Kindness.

Mr. KINDNESS. Thank you, Mr. Chairman.

I have no questions. However, I would like to present my apologies for not being here sooner this morning.

Mr. ERLNBORN. I have one further question.

In scanning very quickly the testimony of one of the other witnesses to be here this morning, Jerome Beigler, I notice a reference in his testimony on page 6 to an APA—and I guess that is the American Psychiatric Association—model State law and a new Illinois confidentiality law.

Does your association have a model law to suggest to the States? Have you worked with the National Commission on Uniform State Laws? Have you worked in that way to try to get good laws at the State level?

Ms. ROGERS. We do not have a model State legislation proposal. The activity of our membership has been through the State legislative committees of the medical record associations. However, the national association has not worked on model legislation with the States at this point.

Mr. ERLNBORN. I recall when I was in the State Legislature in Illinois. We often would enact model State laws, sometimes with practically no amendment from the proposed State law. This included banking laws to have uniformity in handling checks and other mediums of exchange of goods and valuables. It seemed to have worked quite well. We have a banking system that is controlled to a great extent at the State level. We have rather uniform laws State to State.

I am wondering if that is an approach to be examined at least in this area of confidentiality of medical records rather than auto-

matically turning to Washington because it is so much easier and quicker.

Ms. VOLZ. That could be an approach, but it is partly what I was addressing earlier, Mr. Erlenborn—talking about the tremendous variety among State laws which are presently enacted. There are probably about 18 of them that go all the way from the terseness of the one I mentioned in Pennsylvania to much more elaborate ones for other States. There does not seem to be any uniformity among them. I am not aware of what types of guidelines may have been given to them in terms of uniform model laws, but I doubt if very much has been.

It appears that the State laws which have been enacted in some instances literally pick up portions of passages from the Privacy Act or other proposed legislation by other States and other organizations. They are simply submitted in toto without any variance at all. There is where you get into trouble because they have no consistency.

Mr. ERLBORN. I think that is often the condition that leads to activity on the part of the Commission on Uniform State Laws. Maybe we are just at the beginning of the process.

Thank you very much.

Mr. DRINAN. I share the reservations of the gentleman from Illinois, Mr. Erlenborn. I know that colleges, for example, have accreditation all done by voluntary means. The Uniform Commercial Code was developed and is totally consistent in the 50 States.

In any event, as Mr. Erlenborn suggested, we are at the beginning, I take it, of the resolution of a problem which apparently is somewhat widespread.

Are there any other questions?

Mr. KINDNESS. I would like to pursue one avenue of questioning.

Is there any experience either of you have, or have knowledge about, with State laws relating to patient access to medical records, satisfactory or unsatisfactory? What sort of guidance might we get from experiences in States with such laws in place?

Ms. VOLZ. I do have some personal experience in that area. Pennsylvania has had that kind of law in effect since last May. It was enjoined for a time. Many institutions ignored the enjoiner and allowed patient access. In our hospital, Thomas Jefferson University, which has approximately 21,000 discharges a year, which would give you an idea of patient activity, we have had probably 15 requests from patients for access to medical records. There also have been some inquiries about patients that were related to medical record information but the patient did not quite know how to go about finding what he wanted to know. When he was advised that he could have a copy of his record or come to see it, he was very pleased and in some instances made attempts to do so.

One of the provisions in our administrative policy regarding patient access provided for the psychiatric patient to be able to review his record first with a physician for interpretation. In every instance the psychiatric patient refused that. He wanted to review his record himself.

There were some patients who were interested in seeing whether or not there was potential for medical malpractice. Others were simply curious because they had had nagging questions all their

lives about something that happened to them many years ago and felt they did not have a satisfactory explanation.

In our area the pediatric hospitals have found great interest among parents to obtain access to and copies of the medical records of their children, partly because they are mobile and will need this information to be transferred with the children and, second, because they have some questions about whether or not there are hereditary diseases or other familial problems that they might have as a result of one child's illness.

Does that answer your question?

Mr. KINDNESS. Yes. Would it be possible to quantify the latter portion of that relating to the records in the case of pediatric patients as compared to the time before such a law was in place? This normally would have occurred in some measure. I would think a lot of parents would have obtained access to their children's records for the purposes of transit to another location.

Ms. VOLZ. They do but it rarely goes to the parent. The practice of hospitals has generally been not to allow patient or parent access. The way most health care institutions handle it is to have a request received from the parents or the patient to send it directly to the next facility, rather than going through the patient himself.

Of course the doctor-patient relationship exists between the pediatrician and the parent. However, apparently not all parents feel that is satisfactory.

Mr. KINDNESS. Again, is there any quantification that might be employed in describing the difference here?

Ms. VOLZ. Probably an increase up to as high as 10 percent in the Children's Hospital of Philadelphia in terms of patient-parent access now as opposed to none prior to that. The total of release of information from one health care facility to another might be as high as 5 percent of all patients, 10 percent of all patients, over a long period of time who request their information be sent to a second treating institution or a third. Of all patients seen, that hospital's experience has been approximately 10 percent of all the pediatric parents are asking for information from their children's records, as opposed to none from that direct route before.

Mr. KINDNESS. Would you care to venture any opinion or comment as to whether the current situation as to parent access in the case of pediatric records in particular is better than what existed before with the direct transfer to other institutions?

Ms. VOLZ. That is pure speculation, based on the reaction of patients with whom we have had experience where they seemed to be satisfied, much more satisfied than they were previously, before having had access to the record. Whether or not it has any true beneficial effect would be very hard to measure.

Mr. KINDNESS. In regard to a general population of patients, would it be similar?

Ms. VOLZ. It would be similar.

There is a hospital in New Jersey which has a policy that requires all patients to review their medical records before discharge from the hospital. It is their feeling that the patient is much better able to understand his illness and participate in his home treatment in a much more meaningful way than he ever was in the past. That assumes a certain level, first of all, of interest; second,

knowledge; and, third, commitment to himself. Whether or not that truly has any long-term effect, it will be a long time before we know the answer to that.

Mr. KINDNESS. Thank you very much.

Mr. INGRAM. We talked earlier about the difficulty with State law standards. Could you give us some idea as to how much interstate transfer of medical records there is? Is this common with most of the records?

Ms. VOLZ. This is very, very common because patients receive treatments at any number of places during their lifetime. Even overseas we have requests for information from medical records previously made as a result of treatment at a State-side institution.

Mr. INGRAM. Let's say an insurance company requests medical records and then receives them. Are there restraints placed on the amount of sharing that the insurance company or receiver of the records can have? Are there any restraints at all as to what they can do with the records at that point, once they have received them?

Ms. VOLZ. Not by the health care facilities in the general patient population, but some local and State laws regarding psychiatric medical records, which were recently enacted at least in our State, do require that we advise the recipient of the records that he may not re-release the information. However, that is not in the general patient population for the most part.

Mr. INGRAM. As a practical matter, there is no restraint placed on the receiver of the records as to what that individual or company may do with the records?

Ms. VOLZ. That is correct.

Mr. INGRAM. Normally what check would a hospital provide on a requester of the records? In other words, if I were to send you a letter on the letterhead of an insurance company requesting some records, is there any check that you would go through to determine whether or not the requester of the records is in fact an insurance company? What are the normal standards among the profession?

Ms. VOLZ. First, the normal standard would be to require the patient's authorization for release of that information to you. Very often we already have an indication on the medical record by the fact that the source of funding for that admission was already identified. Usually that is already known to us. Frequently insurance companies that were unknown to the provider who are offering life insurance do request information, but it is stated there that they are providing life coverage or looking for information to determine whether or not they should assume that liability.

The first screen of the request for the information would be by the patient's authorization. If it was not present, the information would not be sent.

Mr. INGRAM. The patient has already given a blanket authorization. In that case would you go beyond that and seek to find out more about the requester?

Ms. VOLZ. Not usually, no. The information would have to be in writing. We would not accept verbal requests over the telephone. A copy of what was sent would be retained in the record for future reference should there be some abnormality or unusual circumstances with an improper request.

Mr. INGRAM. As a practical matter, as long as the request was in writing that would be sufficient?

Ms. VOLZ. And on a letterhead, yes.

Mr. INGRAM. We talked a little bit earlier in your testimony about the fact that often an entire record of an individual would be xeroxed and provided to the requester. As a practical matter, would there be a manner in which you could segregate out sensitive data or the types of data that the particular requester would be interested in?

Ms. VOLZ. Yes. The way that would be handled would be to have the requester specify exactly what he is interested in and provide that portion of the record only and block out the remainder.

Mr. INGRAM. Would this be prohibitive in terms of the cost to the record manager?

Ms. VOLZ. It could present some difficulties in selectivity of passages from the record, but costwise it would not be prohibitive.

Mr. INGRAM. Do you have any estimate of the cost of the administration's bill, or whether or not this cost would be any greater than the current expenditure for records management in a particular hospital?

Ms. VOLZ. We do not perceive those costs being inordinate. As has already been stated, there probably would be startup costs in terms of notices to the patients that this is what existed. Many of the health care institutions already have patients' bills of rights and admission-type information which is given to them, telling them about their association with the health care institution, which include passages that say, "You may have access to your medical records. We will offer an interpretation of the content to you." Those costs were not prohibitive when they were done.

Mr. INGRAM. Would it require a hospital to go out and double the size of its records staff?

Ms. VOLZ. No, I do not think so.

Mr. INGRAM. Thank you.

Mr. DRINAN. Mr. Gellman.

Mr. GELLMAN. I would like to ask one question based on your statement that data compiled as part of a research project should not include patient identifiers without the consent of the patient. The research community tells us this would interfere substantially with the conduct of some research studies, particularly longitudinal studies. Would you comment?

Ms. VOLZ. It would increase the difficulty for researchers, but in many, many instances the patient is identifiable through a number. We question whether or not it is necessary in most of the instances of research to actually identify the patient in any other way except by that number. It is always retrievable by individual name and address if you need to followup the patient because of specific information that you learned in the research program of which the patient should be aware.

I am thinking of some public health issues—for instance, such as Legionnaire's disease—that could and should have patient identification. However, the majority of the type of research that goes on with which we are familiar in the health care delivery system does not, in order to be effective, need as much individual identification as perhaps some people are saying.

Mr. GELLMAN. Are you suggesting when information is released to a researcher that it might include an identification number that the hospital could use to track down a patient later on?

Ms. VOLZ. Yes.

Mr. DRINAN. Mr. Morr.

Mr. MORR. You mentioned the Joint Commission on Accreditation of Hospitals and HEW established four standards for medical records. Do those standards provide much guidance in terms of access to medical records?

Ms. VOLZ. No.

Mr. MORR. Would it be possible through those bodies to provide standards short of Federal legislation?

Ms. VOLZ. I think it would be. The joint commission particularly would be very effective in this. The only areas in the delivery system that would not be covered would be the ones that are presently not included under the joint commission standards—for instance, ambulatory facilities. Of course with the trend in delivery systems going toward more ambulatory care, that could be a big area that is not covered.

Mr. MORR. Is there a professional body that covers ambulatory—

Ms. VOLZ. They have their own organizations. It is my understanding that many of them are voluntary.

Mr. MORR. One of the things about which I am concerned is whether or not a doctor reviews patient records with a patient. You mentioned, or Ms. Rogers mentioned in her testimony, that some States provide a procedure for doctors to review records. Do you think that procedure is beneficial?

Ms. VOLZ. Usually it is. The only problem with it is it would be a horrendous thing for doctors to have to do in terms of time with all of their patients.

Mr. MORR. Do you know of the existing State laws how many either require or recommend that kind of thing?

Ms. VOLZ. No, sir, I do not.

Mr. MORR. Would access to medical records by patients, untrained laymen, lead to some misunderstanding of those records?

Ms. VOLZ. It could. First, it would be difficult for the patient to understand the handwriting in many instances. Second, it would be hard to know what the meaning of the medical terms was. Some of the jargon that is used in health records has been misunderstood by patients in my own personal experience. Therefore, it would be advisable if a physician or a patient advocate could interpret to patients specific aspects about the medical care.

However, very often in our experience when patients have looked at their records they wanted to know certain details that were recorded about them—for instance, about their alcohol history or other personal details—to see whether or not they were in there. They did not comment to us beyond that point, however.

Mr. MORR. You mentioned some patients look at their records to see if there is a possible case of medical malpractice.

Ms. VOLZ. Yes.

Mr. MORR. Do you think the lack of understanding of this jargon would increase or decrease the likelihood of malpractice cases?

Ms. VOLZ. I think it is a real risk. It has been in about 2 cases of about 12 to 15 that we have had where malpractice suits have evolved. However, I think the same ones still would have evolved whether or not there was patient access or not. The patient was reinforcing his suspicion that there was reason for suit in the first place. It would probably speed up the process. As you know, at present a suit must be instituted in most instances to have access unless there was voluntary access.

Mr. MORR. I have a question for Dr. Beigler. It is this: Should a patient have access to information obtained by a doctor or a psychiatrist that is obtained in confidence from a third party? Are there problems there?

Ms. VOLZ. We can see problems there, yes.

Mr. MORR. What restrictions to access would you recommend to deal with that.

Ms. VOLZ. To the secondary access?

Mr. MORR. That is right.

Ms. VOLZ. That there be agreement by the person who recorded the information, the third person or second person who recorded the information, that that be reviewed by that individual. My inclination would be to refer the patient to the person who recorded the information in any instance.

Mr. MORR. Thank you, Mr. Chairman.

Mr. DRINAN. Thank you. It is a different type of experience these days when somebody recommends more regulation and another Federal bureaucracy. So we welcome you and thank you for your testimony.

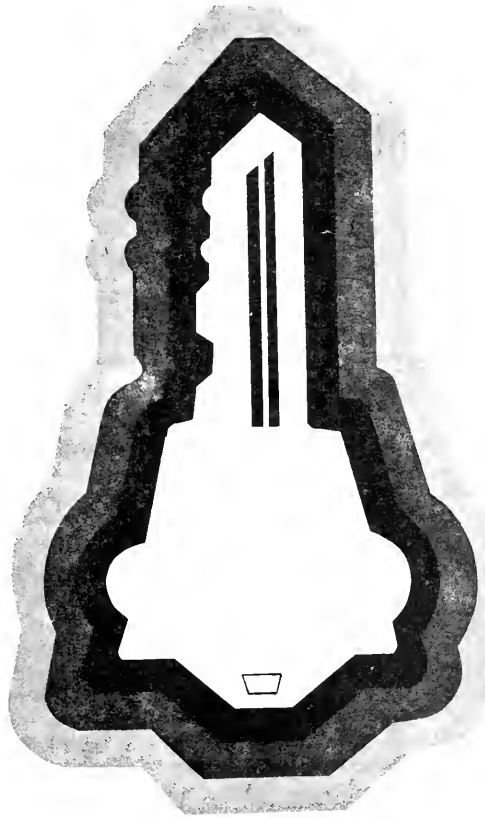
I know you will be in touch with counsel if you have any additional points.

[Additional material and letter supplied by Ms. Rogers:]

Confidentiality of Patient

Health Information

A
Position
Statement
of
the
American Medical Record Association





The basic research and assembly of this material, which now becomes an AMRA Position Statement, was first prepared as a Report by the Legislative Committee of the Pennsylvania Medical Record Association in 1976-77, as funded by AMRA's Executive Board. For these efforts, AMRA is most grateful.

That Report was then modified and subsequently adopted by the AMRA Executive Board in December 1977.

Confidentiality of Patient Health Information

A

Position Statement

of

the

American Medical Record Association

Preface

The Executive Board of the American Medical Record Association is proud to present this confidentiality document which states our position regarding the appropriate collection, dissemination and protection of an individual's personal health information.

At this time, when legislation is being prepared at the national, state and local levels regarding protection of privacy, confidentiality and freedom of information, it is imperative that our Associ-

ation and its members, who are responsible for development of ethical practices to safeguard the information entrusted to their care, clearly affirm their position in this regard—to health care providers, third-party payors, government agencies, national and state health officials and legislators.

The Executive Board strongly encourages each member to work diligently toward implementation by all health care providers of the letter and spirit of this report, including adoption of policies based on the model included herein by all health care providers.

Table of Contents

- I. Introduction
- II. Philosophy
- III. Current Usage of Patient Health Information
 - A. Release of Information
 - 1. Confidential Information
 - 2. Non-confidential Information
 - B. Users and Uses of Health Record Information
 - A. Health Care Providers, Institutional and Individual
 - B. Payors for Services, Private Insurance Plans, Government Insurance Plans and Programs.
 - C. Social Users
- IV. Problem Areas In The Use of Health Information
 - A. Ownership of the Health Record and Health Information
 - B. Patient Education
 - C. Nature and Extent of Information Collected, Stored, and Accessed
 - D. Informal Consent
 - 1. Blanket Consent
 - 2. Prospective Consent
 - 3. Perpetual Consent
 - E. Security Policies and Procedures
- V. Emergence of Privacy As a Public Issue
- VI. Model Policies for Maintenance of Confidentiality of Patient Health Information
 - 1.0 Data Collection
 - 2.0 Storage
 - 3.0 Access

I. Introduction

The American Medical Record Association (AMRA) has traditionally been of service to its members and other health care professionals and agencies by providing guidance in the development of policies and procedures to those concerned with the collection, storage and dissemination of health care information.

AMRA has, since its founding in 1928, been committed to the highest ethical standards for its member practitioners. This position statement reflects a continuing concern in the development of laws, regulations and policies affecting health care information.

AMRA's members are, by training and experience, qualified to provide leadership in information systems which serve the needs of the patient, the institution and the public.

Through this position statement, AMRA establishes the concerns of its members over the abuses of confidentiality of health care information.

II. Philosophy

The primary purposes of the medical record are

- a. To document the course of the patient's health care.

- b. To provide a medium of communication among health care professionals for current and future patient care.

In order to fulfill these purposes, significant amounts of data must be revealed and recorded. The patient must be assured that the information shared with health care professionals will remain confidential, otherwise the patient may withhold critical information which may affect the quality of the care provided.

Economic issues, social issues, and technological advances have eroded the traditional relationship of confidentiality which exists between the patient and health care professional. Substantiation of payment claims has generated an increasing number of requests for information from patient health

records. At the same time, the increase in the amount of computerized health data, the development of large data banks and the advancement of record linkage, pose a threat to the privacy of medical information. The public is generally unaware of this threat and the consequences of a loss of confidentiality in the health care system. Adequate measures to safeguard medical privacy must be established.

AMRA recognizes that patient health information provides a sound data base for a variety of legitimate activities. Through this statement, AMRA reaffirms the patient's right to privacy, including the privacy of the medical record. While the patient does not have the property right to the record, he should have the protected right of information. Further, in keeping with the spirit of informed consent, AMRA supports the right of the patient to have access to his own medical record, unless there are specific contraindications such as: a. Minors, b. Those deemed legally incompetent, c. Specific restriction by attending physician that access could be detrimental to the patient.

Therefore, subject to applicable authorized provisions, release of any individually identifiable medical information for any purpose other than direct patient care, must be done only with the expressed authorization of the patient or his authorized agent.

Further, AMRA recommends greater emphasis on the patient's right to privacy through: a. The establishment of written policies for the collection, storage and dissemination of information, b. Ongoing educational programs for all staff and personnel to enforce these policies.

With respect to this right of privacy, AMRA urges the development and implementation of programs to:

1. Protect the patient from invasion of privacy by protecting against indiscriminate and unauthorized access to confidential health information;
2. Promote appropriate usage and maintenance of confidentiality once health information is disseminated to authorized persons;
3. Educate the patient and the public to: a. Their rights of confidentiality, b. Their right to restrict or limit dissemination of identifiable medical information, c. Their right of access to that information.

III. Current Usage of Patient Health Information

A. Release of Information

Health care facilities receive and respond to numerous requests for information from the medical records in their care. The requests may be written, by telephone or in person, from a broad spectrum of users. The responses are usually written, but in emergencies, may be given by telephone or to the patient or his representative. The health care facilities ordinarily consider the information to be released to fall into two categories:

1. "Confidential" information which requires the patient's written authorization or permission to release.

Confidential information is provided to users such as insurance companies, credit agencies, attorneys and others who will use it for non-patient care purposes. The authorizations are obtained from the patient by the insurance company, attorney, etc., at the time the initial agreement is made. Many are worded to permit the collection of information from any future medical records the patient's health care may generate. On some occasions, "confidential" information may be released without the patient's written authorization, but with his implied consent, usually to those who are currently caring for the patient. A record of what information and to whom it was released and a copy of the authorization are usually kept as part of the original medical record.

2. "Non-confidential" information or that information which may be released without the patient's authorization.

Most health care institutions have policies, procedures and systems for the controlled dissemination of information from their medical records to appropriate users.

B. Users and Uses of Health Record Information

The medical record is a compendium of information about an individual patient during the course of treatment of an episode or episodes of illness(es), or while maintaining an individual's state of health.

The record is made up of components, arranged in a logical sequence. The components include the physical and mental history of the current and previous illness, social factors which may contribute to the illness such as job, marital or other

personal conflicts, the findings on physical examinations, results of diagnostic tests such as x-rays, electrocardiograms, laboratory values, findings and opinions of consulting specialists, the treatment prescribed, a description of the patient's response to that treatment (or lack of response), diagnoses, operations and the plans for and goals of follow-up care. The primary reason for the collection of this sometimes voluminous and sensitive information is patient care.

The content of the medical record is developed as a result of the interactions of the members of the health care "team" who use it as their communication tool. The "team" is an interdisciplinary group which includes physicians, nurses and numerous allied health personnel.

USERS OF MEDICAL RECORDS

A. Health Care Providers, Institutional and Individual (Primary Users)

B. Payers for Services, private insurance plans, government insurance plans and programs (Secondary Users)

They inform and advise each other through their entries in the record about their findings, observations, opinions and treatment of the patient. At the conclusion of treatment of the episode of illness the record is sent to the medical record department where it is processed.

Medical record department personnel are responsible to design and implement a system to provide for evaluation, retention and future utilization of patient information. Patient information is used to plan patient care, perform medical research, evaluate patient care and provide information to authorized users.

Current users of medical information and the purposes for which the information is used may be classified as follows:

USES OF INFORMATION IN MEDICAL RECORDS

1. as a medium of communication among health care providers during the current episode of illness
2. as a reference for treatment of future illnesses
3. for training of physicians and other personnel—to assist students to relate theory with medical practice
4. for prospective and retrospective evaluation of the quality of patient care through review and analysis of patterns of care as documented in the medical record
5. for promotion of effective and efficient use of facilities, equipment, services, personnel and financial resources through statistical analysis of information abstracted from the medical record
6. for documentation of voluntary compliance with standards for accreditation of the institution
7. for research aimed at the improvement of treatment, assessment of disease detection methods, assessment of the effectiveness of medication and other treatments through study of appropriate cases
8. for documentation which demonstrates conformity to government regulations
9. follow-up care of patients with long-term illnesses and assessment of the efficacy of the care given
1. for substantiation of patient claims for payment of health care services
2. for audits of claims for health care services and professional fees
3. to monitor the quality and equity of care and services rendered to those insured
4. to assess and control the cost of health care services to those insured

C. Social Users

- | | |
|--|---|
| 1. Public Health Agencies | 1. in surveillance of diseases of epidemiologic significance through statistical analysis of information abstracted from medical records |
| 2. Medical and Social Researchers, institutional and extra-institutional | 1. for investigations of disease patterns, effects of disease on functions of daily living, including occupational health and safety |
| 3. Rehabilitation and Social Welfare Programs | 1. in determination of need for specific types of rehabilitation programs through analysis of incidence data

2. in development of individual rehabilitation and training plans for participants in programs for the handicapped, retarded and drug and alcohol abusers |
| 4. Employers | *1. for administration of employer-provided health insurance plans
*2. for determination of employment suitability

3. in treatment and analysis of job related injuries and correction of occupational hazards

4. to determine disability |
| 5. Insurance Companies | *1. in determination of risks in writing insurance

2. in determination of liability for claims |
| 6. Government Agencies: federal, state and local | 1. for allocation of government resources for schools, health care facilities, education institutions, etc. based on vital statistics submitted from medical records |
| 7. Education Institutions | *1. for assessment of suitability for admission to selected education programs

2. for maintenance of student and employee health programs |
| 8. Judicial process | 1. in adjudication of civil and criminal matters through use of the medical record as evidence through the legal process

2. in judicial process for involuntary admission of mentally ill. |
| 9. Law enforcement and investigation | *1. in criminal investigation
*2. for security clearance programs |
| 10. Credit investigation agencies | *1. for determination of credit eligibility |
| 11. Accrediting, Licensing and Certifying Agencies | 1. for demonstration of individual fulfillment of criteria for professional licensing by a state government agency

2. to ascertain competence of practitioners

3. for determination of compliance with criteria for hospital based education programs

4. as documentation of compliance with standards for institutional accreditation |

12. Media: press,
radio, TV

1. for announcements of developments in medical research
2. for reporting of health hazards, diseases affecting the public health and newsworthy events.

*May in some instances be improper use.

IV. Problem Areas in the Use of Health Information

In a record-generating society, the maintenance of confidentiality is subject to a number of pressures through all stages of collection, storage and retrieval. The result of these pressures is most often the unauthorized access to information, either through routine indiscriminate dissemination or through failure to establish adequate policies and procedures governing individual and organizational access to identifiable data. There are several relevant problem areas which are to some degree interrelated.

A. Ownership of the Health Record and Health Information

The issue of ownership of the patient health record, as distinct from ownership of the information therein, is one which has not been resolved. While the patient may to some extent control access to his record by refusing consent to release of information, in many states he himself has access only through litigation or in accordance with the policy of the individual institution. In the private sector*, the physical document itself is not the patient's property, and in few cases is a full copy made available to him. In addition, many health care providers consider the document and its contents to be their own property, generated by them; by virtue of this "ownership" they feel themselves justified in exercising control over its release to the patient. For the most part, providers and institutions have failed to fully address the issue of ownership and its attendant implications for policy and procedure development. There may be somewhat casual access to the record by almost anyone *except* the patient—by transporters and processors of various levels of training and reliability. Access may also be obtained by unauthorized and in many cases unidentified users, both internal and external to the facility. Another by-product of refusal of patient access has been the recording of inaccurate and inconsistent in-

formation with minimal review conducted for relevance.

B. Patient Education

For the most part, patients are unaware of the full range of purposes for which the record is used, or of policies governing the release of information. They are mainly aware of those uses personal to them, such as planning of individual health care, or protection of legal interests in such matters as personal injury suits or applications for life insurance. Less well-known uses are those of medical care evaluation, research (whether internal or external to the institution), planning for facilities, and meeting the requirements of licensing, accrediting, and certifying bodies. Few have any concept of the quantity of information released to third parties, governmental or private.

There is growing emphasis on patient knowledge of self-care as appropriate criteria for patient care audits. This concept must be broadened to include patient knowledge of the record, its contents and its uses. It is the responsibility of the health care providers to act as educators—to focus on the knowledge deficit in the patient population and by correcting it to include the patient as an active contributor to the health care team, to the accuracy of his record, and to the assurance of its appropriate use.

C. Nature and Extent of Information Collected, Stored and Accessed

The health information gathered today is substantially different from that gathered in an era preceding the multipart form and word processing. Patient mobility and professional specialization mean that one family physician no longer carries the family health history in his head, with the aid of a few pertinent notes. Multiple providers mean that the record is a major central communication tool. Also, external agency needs and legal requirements affect data collection; social and family histories are now required by both accrediting and governmental agencies, for example. Thus, more and intimate detail of the patient's personal habits,

*as opposed to governmental institutions.

social relationships, emotional and mental status, attitudes and preferences is being collected as part of medical data. This information is generally disclosed willingly by the patient but with the understanding that the confidentiality of the communication will not be breached. Routine processing, storage and retrieval functions are performed on the record as a whole; usually no data are screened or removed at any point. Consequently, a great deal of highly sensitive identifiable information may be retained for decades without review for relevance or propriety.

The sequel to prolonged storage of all information as a unit is often the release of that entire unit. A notable example is that of information released to insurance companies whose attempts to insure payment for no more care than is necessary have led to demands for far more data. These demands, together with facilities' budgetary crises and personnel reductions, have led to the frequent practice of indiscriminate photocopying in order to keep up with the workload. This results in volumes of unedited data released to third parties without restriction of use to a specific need and without requiring destruction of the information or of personal identifiers as quickly as possible. It has, in fact, proven almost impossible to discover what happens to such information; whatever policies for identification, retention and release exist within the agencies have seldom been made known to either the public or the health care providers.

D. Informed Consent

As may be inferred from the preceding paragraphs, the practice of obtaining informed consent is notable chiefly by its absence. There are at least three facets to this particular problem.

First, in "blanket consent", patients or guardians are asked to sign releases which allow facilities to disseminate "any and all" identifiable information to whomever is offering a benefit or service to the patient. The patient is not himself "informed" as to the full extent of the record's content, which segments of it will be open to third party access, or what will happen to the information once it is in the third party's possession. "Blanket consent" does not serve to instill a sense of responsibility in the collectors, storers and users of patient data.

Second, difficulty arises from the common third-party practice of requesting "prospective consent", or consent of release of information prior to treatment. This means that the patient is consenting to

the dissemination of that which is not yet collected, a practice which precludes any intelligent decision-making on the part of the patient.

Third, most insurance companies request a form of consent which could be construed as "perpetual consent," since there is no attendant time limit set for validity of the consent. With other requestors, health care institutions vary in the time limits within which they accept patient consent as "current." In some cases health care institutions are adopting more stringent limits, but there is no uniformity of policy in this area.

E. Security Policies and Procedures

Failure to fully acknowledge that the facility owning an information system is directly responsible for its uses has led to practices which do not always support the ethical principles of confidentiality. This applies both to intra- and to inter-institutional transactions. In a health facility a large number of persons handle personal information, often at locations remote from any central control area. Partly as a consequence of numbers and inconvenience, close monitoring of their activities is not routine. The categories of persons involved include transporters (e.g. patient escorts, elevator operators, car drivers), handlers (e.g. unit clerks and managers, admissions and billing clerks), internal processors (e.g. key punch operators, chart analysts, file clerks) and external processors (e.g. services for transcription, subpoenas, photocopy, microfilm, data processing, coding, and off-site storage).

The identification of legitimate investigators poses special problems. Law-enforcement officers, for example, sometimes are seen as authority figures and obtain unauthorized information from personnel who are uninformed or somewhat intimidated. Newspaper reporters, credit investigators and a variety of others without any legitimate need-to-know have been known to assume an almost limitless range of identities, including patient relatives, priests, messengers, and physicians, in order to obtain health information.

In an adequate information control system, identification of categories of authorized processors must be followed by clear identification of persons appropriate to perform such functions. Physical, technical and procedural security measures are developed with a degree of refinement dependent to some extent on the adequacies of the personnel control system. None of these controls have been

sufficiently expanded to reflect record-keeping practices in today's society.

The emergence of the computer's role in the health care system increases the capacity for information storage and transfer and provides a new range of possibilities for unauthorized access to patient data. The image of giant and possibly unrestrained mechanical data banks has, however, captured a sufficient number of imaginations to result in several studies, publications and legislative proposals designed to assess and minimize the risks associated with automated record-keeping. What has not yet occurred is the translation of these concerns to the manual system. Both manual and computer systems face such risks as: untrained generators, processors or accessors who can inadvertently alter, release or lose information; natural forces such as fire or flood which can destroy any information improperly stored; use of information for purposes not specified at the time of consent to release; and information transferred or sold with malicious intent.

Few data processing policies and procedures are comprehensive, detailed, and applicable to all forms of processing. Operational standards usually are designed in accordance with those of other health-care facilities, whereas the best models are more likely to be found within high-risk industries. Standards devoted to protection of software—the record—rarely approach the caliber of those developed for the testing of expensive hardware. If such deficiencies are corrected, the computer may yet prove the greatest asset to confidentiality rather than the greatest liability.

V. Emergence of Privacy as a Public Issue

In the wake of the Watergate revelations, perhaps no issue has generated more attention than that of privacy. The Privacy Act of 1974 imposed controls on the Federal sector with regard to record-keeping on individuals and specified rights of individuals to gain access to those records maintained by governmental agencies, with the opportunity to correct inaccurate data.

The Privacy Act of 1974 also created the Privacy Protection Study Commission, with a mandate to undertake a study over a three-year period to investigate the feasibility of extending provisions of the Privacy Act to the private sector. The Commission has investigated the record-keeping practices in many areas of the private sector, including

medical records, employment and personnel records, education records, records of social agencies, and private investigation firms. The report and recommendations of the Privacy Protection Study Commission were transmitted to President Carter and the Congress on July 12, 1977. This report, *Personal Privacy in an Information Society*, includes a chapter titled "Record Keeping in the Medical-Care Relationship," which summarizes information gathered in hearing testimony and research, and delineates the conclusions and recommendations of the Commission with regard to medical documentation.

The Commission conclusions indicate that medical records now contain more information, are available to more users, are less well controlled and are used for more non-medical purposes than ever before. Further, the Commission concludes that, in many instances, patient authorization to release information may not be consent freely given, when the patient's choice may be to consent or to forego employment, insurance or other benefits. In addition, despite the increasing number of uses and users of a growing volume of patient health information, it is still rare for the patient to exercise his right to direct access, to have the opportunity to review it for completeness, accuracy or timeliness or to control the disclosure of information.

The Commission recommendations have three stated objectives: ". . . (1) to minimize intrusiveness; (2) to maximize fairness; and (3) to create a legitimate, enforceable expectation of confidentiality."¹

In a separate study, *Computers, Health Records and Citizen Rights*, conducted under the auspices of the Institute for Computer Sciences of the National Bureau of Standards, Alan Westin of the Department of Public Law and Government at Columbia University has stated that "Medical records and health data are being used today in an enormous variety of settings, with computerization present in all of them. Our report has traced such use in doctor's offices, clinics, health centers, and hospitals, in governmental and private facilities; in acute and ambulatory care; in physical medicine and psychiatric treatment; where patients could choose their health care and where they are under various institutional controls (prisons, the army,

1. *Personal Privacy in an Information Society: The Report of the Privacy Protection Study Commission*, July 1977, USGPO, Wash., D.C. 20402 stock #052-003-00395-3)

mental hospitals, etc.). We have seen that beyond primary care lie important uses of personal medical data for service-payment, quality care review, and all the social processes . . . from credit, employment and licensing to law enforcement, social research, and political life."²

The Westin report is a comprehensive review of the nearly infinite ways that personal health information is used, by both appropriate and unauthorized users, for legitimate, questionable and clearly inappropriate purposes, for transactions in the best interest of the patient, as well as for those which are detrimental to the patient and others.

The medical record practitioner, as "custodian of the records" is increasingly on the horns of a dilemma: how to fulfill the obligations of record-keeping in providing needed information to serve the patient, the health care facility, and the community, while protecting the patient from unauthorized, inappropriate or unnecessary intrusion into the highly sensitive and personal data of his health record.

Under the watchword of accountability, the long-held tradition of confidentiality of health information has been gradually eroded. Third party payors, both private and governmental, demand more and more personal health information to process a claim, and routinely visit hospitals to review selected patient health records in toto for the purposes of claim verification and audit.

The proposed procedures for Review of Hospital Services for Professional Standards Review Organizations (Federal Register, January 25, 1977, Part II), state in section 101.715 Examination of the operation and records of hospitals, that "(a) Each PSRO is authorized to inspect the operation and records pertinent to the health care services rendered to Title V, XVIII or XIX patients of any hospital in the PSRO area in which services are provided and may require such hospital to provide copies of such records to the PSRO. . ."; further, this section states that, "(b) a PSRO may utilize the records of patients *other than those covered under Titles XVIII, XIX and V*, where access to their records is authorized by the hospital." (emphasis added) Not only have patients who accept benefits under these programs relinquished their rights to privacy of their health records as a

condition of acceptance of benefits, but it would now appear that *all* patients, regardless of their payment status, may have their "confidential" health records open to review without the benefit of their knowledge or consent.

The increasing pressures of fiscal accountability, malpractice, risk management, accrediting, licensing and regulatory agencies, public health agencies and third party payors, with their accompanying information requirements, have subjected hospitals, and medical record departments in particular, to demands for patient health information which are staggering. While the work load has increased considerably, employment of sufficient manpower has been prohibited by fiscal constraints facing hospitals. Therefore, medical record departments have made heavy use of photocopy equipment and other document replication media which decrease the effectiveness of control over the types and amount of information released from patient records.

Health care facilities have also turned to automated information handling systems in an attempt to cope with the growing demands for more information in more sophisticated formats. The recipients of this information have turned to such electronic systems as well, in order to process and review the data received, e.g., the massive data systems of Blue Cross/Blue Shield, Medicare, Departments of Welfare, private insurance carriers, and most recently, the PSRO's. The technology that has evolved to manage the "health information explosion" has, in turn, created new problems of data security.

In his conclusion to *Computers, Health Records and Citizen Rights*, Alan Westin states, "As American society redefines and reorganizes its health-care system in the coming decade, it will have to make increased use of computer technology to manage the rivers of data that will be generated . . . If the question is not whether but how such technology will be used in health care, American Society has one nonnegotiable condition for this process: basic citizen rights cannot be made a casualty of technology-assisted health systems. To do so would be to betray the tradition of Hippocrates, and ultimately to dehumanize health care itself."

The health care community has been acutely aware of the insidious erosion of the confidential relationship between the patient and the health care professional through the growing requests for

2. Westin, Alan F., *Computers, Health Records and Citizen Rights*, U.S. Department of Commerce; National Bureau of Standards Monograph 157, USGPO, Wash., D.C. December 1976.

the information shared in this relationship for the purpose of patient care.

The health care community has taken some steps to try to curb this intrusion, and momentum is gathering for more definitive action. In 1973, the American Hospital Association adopted "A Patient's Bill of Rights," which included statements asserting the patient's rights to privacy of his medical care program as well as of all communications and records of his care. In 1974, AMRA adopted a Position Paper on the Confidentiality of Medical Information, recommending the "development and implementation of programs to: (1) protect the patient from invasion of privacy as a result of indiscriminate and unauthorized access to confidential health information and (2) promote appropriate use of medical information once it is disseminated to authorized persons." Also in 1974, at the initiation of the American Psychiatric Association, fifty medical and consumer groups met in Key Biscayne, Florida, to discuss their concerns about the confidentiality of health records. This meeting provided the impetus for the formation of National Commission on Confidentiality of Health Records. In June, 1976 the AMA House of Delegates approved a bill for model state legislation on the confidentiality of health care information.

These are but a few examples of expressions of concern from the health care community. Most of these expressions have been in the form of guidelines or policy statements, without the force of law. A version of the AMA Model bill has been introduced in five state legislatures; however, it has not yet been enacted in any state.

As these guidelines and policy statements have been propounded, the requirements for release of patient health information have continued to grow, both through regulation and through the requirements of private agencies. Integral to the concerns of privacy and confidentiality of patient health information is the issue of patient authorization and the conditions under which a patient consents to release of information from his health record. At this time, it is unusual for a patient to gain direct access to his health record. Without the opportunity to review the contents of his health record, a patient is placed in the untenable position of consenting to the release of information of which the patient has no knowledge. This situation is incompatible with the rationale of informed consent. Further, many patients sign blanket prospec-

tive consents to release of medical information as a condition of participation in both private and public health insurance programs. Here, again, the patient is required to consent to the release of information which does not yet exist, and therefore, cannot be considered *informed* consent.

The public has been increasingly subjected to intrusion by a variety of agencies into their personal lives; in recent years, the greatest intrusion into the "medical life" of the individual has been made in the name of accountability. The public has demanded this, too; however, the public at large does not recognize the consequences of these demands nor the price in individual freedom and privacy that is paid to assure that health dollars are spent most appropriately and most effectively. In addition, those who have been pressed to be accountable, have, in some cases, been overzealous in carrying out their charge, and have demanded far more information than necessary to process a claim, to determine eligibility, or to assure quality.

There is now a need for a swing of the pendulum back, for a balance between the needs of society to know and the rights of the individual to be free from unwarranted intrusion into his personal life. AMRA acknowledges the need for patient health information in substantiating health insurance claims, in litigation, and in medical care evaluation. The critical issue is how much information is needed to carry out these functions, under what conditions should the information be gathered and disseminated, who should have access to the information and what criteria should be used to determine legitimacy of purpose.

Many of these questions become moot if the patient is fully informed about the existence of information about his health care, has access to it and can exercise maximum control over its dissemination. In the spirit of this philosophy, AMRA endorses the following model policies for maintenance of confidentiality of health information, and actively supports their implementation.

Model Policies for Maintenance of Confidentiality of Patient Health Information

General

The health record is the property of the health facility and shall be maintained to serve the patient, the health care providers and the institu-

tion in accordance with legal, accrediting and regulatory agency requirements. The *information* contained in the health record belongs to the patient, and the patient is entitled to the protected right of information. All patient care information shall be regarded as confidential and available only to authorized users.

1.0 Data Collection

1.1 The types and amount of information gathered and recorded about a patient shall be limited to that information needed for patient care. Supplementary data which is *not* required for patient care but desirable for research, education, etc., may be recorded with the permission of the patient, following explanation of the purpose for which the information is requested.

1.2 All individuals engaged in the collection, handling or dissemination of patient health information shall be specifically informed of their responsibility to protect patient data and of the penalty for violation of this trust. Proven violation of confidentiality of patient information shall be cause for immediate termination of access to further data, and immediate termination of any employer-employee relationship with prejudice for rehire. This policy shall be made known to all employees at the time of employment and each employee shall indicate understanding of this policy through a signed statement at the time of employment, kept with employee's personnel record. An example of statement is attached. Once yearly they will read the policy and again sign a statement of compliance and understanding.

Note: Continued development of State and Federal legislation to impose penalties of fine and/or imprisonment for such violation is recommended.

1.3 The collection of any data relative to a patient, whether by interview, observation or review of documents, shall be conducted in a setting which provides maximum privacy and protects the information from unauthorized individuals.

2.0 Storage

2.1 All primary health records shall be housed in physically secure areas under the immediate control of the Director of the Medical Record Department.

2.2 Secondary records, indices or other individually identifiable patient health information maintained by the institution are subject to the stated policies for maintenance of confidentiality of patient health information. A listing of these

secondary records with a brief description of content and location shall be maintained in a central location, preferably in the Medical Record Department.

2.3 Primary and secondary health records shall be retained according to legal, accrediting or regulatory agency requirements, then destroyed according to an approved institutional retention schedule unless there is specific need for preservation of these records. The method of destruction shall be specified and the actual destruction witnessed or attested to in writing by the individual(s) responsible for destruction.

2.4 Original health records may not be removed from the premises, except on order of subpoena.

2.5 Access to areas housing health information records shall be limited to Medical Record Department personnel. The sole exception to this policy shall be the individual designated by the Director of Medical Records for access at times when the Department is not staffed. Health records must be available and accessible at all times for patient care.

2.6 When in use within the institution, health records should be kept in secure areas at all times. Health records should not be left unattended in areas accessible to unauthorized individuals.

2.7 If facsimiles of the health record are provided to authorized internal users, the same controls will be applied for return of these facsimiles as for return of the original health record. Wherever possible, internal users will be encouraged to use the original health record rather than to obtain a facsimile.

2.8 When photocopies or other reproductions of the health record are provided to authorized external users, these copies will be accompanied by a statement:

- a) prohibiting use of the information for other than the stated purpose.
- b) prohibiting disclosure by recipient to any other party.
- c) requiring destruction of copies after the stated need has been fulfilled.

3.0 Access.

3.1 All requests for health records shall be directed to the Medical Record Department.

3.2 Release of information from the health record shall be carried out in accordance with all applicable legal, accrediting, regulatory agency requirements, and in accordance with written institutional policy.

3.3 Health records shall be available for use within the facility for direct patient care by all authorized personnel as specified by the chief executive officer, and documented in a policy manual.

3.4 Direct access to patient health records for routine administrative functions, including billing, shall not be permitted, except where the employees are instructed in policies on confidentiality and subject to penalties arising from violation of these as specified in **1.2**.

3.5 Original health records may not be removed from the premises, except on order of subpoena.

3.6 Subject only to specific contraindications by the attending physician and to any legal constraints such as those governing minors and those adjudicated as incompetent, a patient may have access to his own health record for review upon written request with reasonable notice. A patient may have access to records of his care after discharge and completion of the health record. Photocopies of health record will be provided on written request by the patient and payment of a reasonable fee.

3.7 All information contained in the health record is confidential and the release of information will be closely controlled. A properly completed and signed authorization is required for release of all health information except:

- a) as required by law
- b) for release to another health care provider currently involved in the care of the patient
- c) for medical care evaluation
- d) for research and education in accordance with conditions specified in Policies **3.11** and **3.12** below.

3.8 In keeping with the tenet of informed consent, a properly completed and signed authorization to release patient information shall include at least the following data:

- a) name of institution that is to release the information
- b) name of individual or institution that is to receive the information
- c) patient's full name, address and date of birth
- d) purpose or need for information
- e) extent or nature of information to be released, including inclusive dates of treatment

Note: An authorization specifying "any and all information . . ." shall not be honored

- f) specific date, event or condition upon which consent will expire unless revoked earlier
- g) statement that consent can be revoked but

not retroactive to the release of information made in good faith

- h) date that consent is signed

Note: Date of signature must be *later* than the dates of information to be released

- i) signature of patient or legal representative.

3.9 All requests for information from health records shall be directed to the Medical Record Department for processing.

3.10 Information released to authorized individuals/agencies shall be strictly limited to that information required to fulfill the purpose stated on the authorization. Authorizations specifying "any and all information . . ." or other such broadly inclusive statements shall not be honored. Release of information that is not essential to the stated purpose of the request, is specifically prohibited.

3.11 Following authorized release of patient information, the signed authorization will be retained in the health record with notation of what specific information was released, the date of release and the signature of the individual who released the information.

3.12 Health records shall be available to authorized students enrolled in educational programs affiliated with the institution for use within the Medical Record Department. Students must present proper identification and written permission of the instructor with their request. Data compiled in educational studies may *not* include patient identity or other information which could identify the patient.

3.13 Health records shall be made available for research to individuals who have obtained approval for their research projects from the appropriate medical staff committee and administrator or other designated authority. Data compiled as part of research studies may not include patient identity or other information which could identify the patient unless prior authorization from the patient has been obtained. Any research project which would involve contact of the patient by the researcher must have written permission of the patient's attending physician, or in his absence a physician designated by the current chief executive officer of the facility, and consent of the chief executive officer to conduct this study prior to contact. Research projects which involve use of health records shall be conducted in accordance with institutional policies on use of health records for research.

3.14 The names, addresses, dates of admission or discharge of patients shall not be released to the news media or commercial organizations without the express written consent of the patient or his authorized agent.

3.15 All service organizations which process patient-identifiable health information for the institution shall agree in writing to conditions which:

- a) mandate the security of the patient information,
- b) specify the methods by which the information is handled and transported,

- c) limit the number of types of individuals who have access to the information to those directly involved in processing and
- d) specify the penalty for any violation of security or confidentiality.

3.16 Requests for health record information received via telephone will require proper identification and verification to assure that the requesting party is entitled to receive such information. A record of the request and information released will be kept. ■

SAMPLE CONFIDENTIALITY STATEMENT

I understand and agree that in the performance of my duties as an employee of _____, I must hold medical information in confidence. Further I understand, that intentional or involuntary violation of my employer's confidentiality may result in punitive action including possible fine or imprisonment.

Date	Signature
Date	Signature
Date	Signature
Date	Signature



AMERICAN MEDICAL RECORD ASSOCIATION

875 NORTH MICHIGAN AVENUE • SUITE 1850, JOHN HANCOCK CENTER, CHICAGO, ILLINOIS 60611 | (312) 787-2672

EXECUTIVE OFFICE

May 22, 1979

The Honorable Richardson Preyer
Chairman
Government Information and Individual
Rights Subcommittee of the Committee
on Government Operations
Rayburn House Office Building
Room B-349-B-C
Washington, D.C. 20515

Dear Congressman Preyer:

On behalf of the American Medical Record Association I wish to thank you and the Subcommittee for your recent invitation to us to testify on confidentiality of medical records. Per your request, enclosed is the transcript of the hearings from April 9, 1979 and our comments and signature.

Your letter of April 21, 1979 requested assistance on compiling an up-to-date list of statutes on confidentiality of medical records from various state statutes and a record of any statistics which we have on patient access and correction procedures for medical records. At this time we are in the process of gathering these materials and statistics for the hearing record and will forward them to the Subcommittee as soon as they are available to us. You also requested that we provide detailed comments on the HR 2979 and HR 3444. The AMRA Advisory Panel on Confidentiality will provide a detailed commentary on these bills in the near future. We will forward these comments as you requested.

Again, I thank you and the Subcommittee for your interest in the subject of confidentiality of medical records and for your communication with the American Medical Record Association. I look forward to continued work with you and the Subcommittee staff.

Sincerely,

Jane Rogers, RRA
Director of Legislative Affairs
and Communications

JR:lm

cc: Carolyn Cave, Ph.D., RRA
Executive Director
American Medical Record Association

cc: Lorraine Volz, RRA

Mr. DRINAN. Thank you, Ms. Rogers and Ms. Volz, for your presentation.

Ms. VOLZ. Thank you for inviting us.

[Ms. Rogers' prepared statement follows:]



AMERICAN
MEDICAL
RECORD
ASSOCIATION

NORTH MICHIGAN AVENUE • SUITE 1850, JOHN HANCOCK CENTER, CHICAGO, ILLINOIS 60611 | (312) 787-2672

EXECUTIVE OFFICE

U.S. HOUSE OF REPRESENTATIVES

COMMITTEE ON GOVERNMENT OPERATIONS

SUBCOMMITTEE ON GOVERNMENT INFORMATION AND INDIVIDUAL RIGHTS

Written Testimony

submitted by the

American Medical Record Association

Concerning

Confidentiality of Medical Records

THE AMERICAN MEDICAL RECORD ASSOCIATION

I AM JANE ROGERS, R.R.A., DIRECTOR OF LEGISLATIVE AFFAIRS AND COMMUNICATIONS FOR THE AMERICAN MEDICAL RECORD ASSOCIATION (AMRA), AN ORGANIZATION REPRESENTING MORE THAN 22,000 REGISTERED RECORD ADMINISTRATORS, ACCREDITED RECORD TECHNICIANS AND OTHERS INTERESTED IN MEDICAL RECORDS AND HEALTH DATA. THE PRIMARY PURPOSE OF THE ASSOCIATION IS TO PROMOTE COMPREHENSIVE HEALTH RECORD SERVICES FOR THE WELFARE OF THE PUBLIC.

ONE OF THE GOALS RELATES DIRECTLY TO THE CONCERNS OF THE SUBCOMMITTEE. THIS AMRA GOAL IS TO PROVIDE LEADERSHIP IN PROMOTING APPROPRIATE USE OF HEALTH RECORD INFORMATION IN THE BEST INTERESTS OF THE PUBLIC. THE MEDICAL RECORD PRACTITIONER HAS AN OBLIGATION TO PROTECT THE INDIVIDUAL'S RIGHT OF PRIVACY WITH RESPECT TO THE CONTENT OF HIS MEDICAL RECORD AND TO ASSIST HIM IN UNDERSTANDING THE RELEASE OF APPROPRIATE INFORMATION FROM HIS MEDICAL RECORD EITHER TO FACILITATE HIS CONTINUING HEALTH CARE OR TO ENABLE HIM TO SECURE PAYMENT FOR HIS CARE FROM THIRD PARTY PAYORS.

THE AMERICAN MEDICAL RECORD ASSOCIATION SETS STANDARDS FOR MEDICAL RECORD PRACTITIONERS, AND PROVIDES FOR CREDENTIALING OF PRACTITIONERS. THE EDUCATIONAL PROGRAMS OFFERED TO PREPARE FOR ENTERING MEDICAL RECORD PRACTICE ARE APPROVED ON THE BASIS OF STANDARDS DEVELOPED JOINTLY WITH THE AMERICAN MEDICAL ASSOCIATION. PROOF OF PARTICIPATION IN A CONTINUING EDUCATION PROGRAM IS REQUIRED FOR MAINTENANCE OF CREDENTIALS TO PRACTICE. THE ASSOCIATION PROVIDES A VARIETY OF CONTINUING EDUCATION PROGRAMS FOR ITS MEMBERS.

I APPRECIATE THE OPPORTUNITY AFFORDED BY THIS COMMISSION TO PROVIDE INFORMATION ABOUT CONFIDENTIALITY AND MEDICAL RECORD PRACTICES AND PROBLEMS AS PERCEIVED BY THE MEDICAL RECORD PROFESSION.

PURPOSE AND USE OF MEDICAL RECORD

THE CONCEPT OF "CONFIDENTIALITY" OF MEDICAL INFORMATION IS A MEDICAL TRADITION AS OLD AS THE HIPPOCRATIC OATH - INFORMATION EXCHANGED BETWEEN PATIENT AND PHYSICIAN IS SACRED, PRIVATE, CONFIDENTIAL. IT IS AN ASSUMPTION HELD BY ALL HEALTH CARE PROFESSIONALS. HISTORICALLY, THE PRIMARY PURPOSE OF THE MEDICAL RECORD HAS BEEN THE CARE OF THE PATIENT - TO DOCUMENT THE CAUSE OF HEALTH CARE AND TO PROVIDE A MEDIUM OF COMMUNICATION AMONG HEALTH CARE PROFESSIONALS. ENTRIES ARE MADE IN THE MEDICAL RECORD NOT ONLY BY PHYSICIANS, BUT NURSES, DIETICIANS, SOCIAL WORKERS, PHARMACISTS, PHYSICAL THERAPISTS AND MANY OTHER SPECIALISTS.

IN RECENT YEARS, HOWEVER, OUR SOCIETY HAS SEEN CHANGES IN THE DELIVERY, PAYMENT, AND ACCOUNTABILITY MECHANISMS OF THE HEALTH CARE SYSTEM, WHICH HAVE SUBJECTED HEALTH FACILITIES, AND MEDICAL RECORD DEPARTMENTS, IN PARTICULAR, TO STAGGERING DEMANDS FOR MEDICAL INFORMATION. YOU MAY NOW ASSUME THAT MEDICAL RECORDS ARE USED ONLY FOR PATIENT CARE - BUT JUST LISTEN TO THE POTENTIAL SECONDARY USERS:

- 1) PAYORS FOR SERVICES, PRIVATE AND GOVERNMENT INSURANCE PLANS AND PROGRAMS.
- 2) PUBLIC HEALTH AGENCIES,
- 3) MEDICAL AND SOCIAL RESEARCHERS,
- 4) REHABILITATION AND SOCIAL WELFARE PROGRAMS,
- 5) EMPLOYERS,
- 6) INSURANCE COMPANIES,
- 7) GOVERNMENT AGENCIES,
- 8) EDUCATIONAL INSTITUTIONS,
- 9) JUDICIAL PROCESSES,
- 10) LAW ENFORCEMENT AND INVESTIGATION,

11) CREDIT INVESTIGATION AGENCIES,

AND FINALLY,

12) ACCREDITING, LICENSING AND CERTIFYING AGENCIES.

AS MORE KNOWLEDGE HAS DEVELOPED ABOUT THE IMPACT OF SOCIAL, EMOTIONAL, AND ECONOMIC FACTORS ON MEDICAL CONDITIONS, MORE INFORMATION HAS BEEN SOUGHT AND RECORDED IN THE RECORD ABOUT THE INDIVIDUAL'S FAMILY, SCHOOL, OR WORK SITUATION, AS WELL AS HIS ECONOMIC WELL BEING AND ANY ENVIRONMENTAL FACTORS THAT MIGHT HAVE BEARING ON HIS HEALTH STATUS.

TODAY A COMPLETE MEDICAL RECORD MAY CONTAIN MORE INTIMATE DETAILS ABOUT AN INDIVIDUAL THAN COULD BE FOUND IN ANY OTHER SINGLE DOCUMENT. MEDICAL RECORDS MAINTAINED IN HOSPITALS AND OTHER MEDICAL CARE SETTINGS ARE NOT GENERALLY RECORDS OF SINGLE EPISODES OF ILLNESS: RATHER THEY ARE COMPILATIONS IN A SINGLE RECORD OF ALL EXAMINATION AND/OR TREATMENT EPISODES IN AN INDIVIDUAL'S CONTACT WITH THAT INSTITUTION OVER TIME, WHICH CAN ENCOMPASS MANY YEARS OR EVEN A LIFETIME. IT IS FOR THIS REASON THAT THE PRESERVATION OF THE CONFIDENTIALITY OF THIS INFORMATION AND PROTECTION AGAINST ITS IMPROPER USE IS SO IMPORTANT TO THE INDIVIDUAL'S CIVIL RIGHTS.

CONTENT OF RECORD AND DOCUMENTATION STANDARDS

CURRENT DOCUMENTATION STANDARDS REQUIRE THAT MEDICAL RECORDS CONTAIN SUFFICIENT INFORMATION TO IDENTIFY THE PATIENT, TO SUPPORT THE DIAGNOSIS, TO JUSTIFY THE TREATMENT, AND TO DOCUMENT THE RESULTS ACCURATELY.

A TYPICAL HOSPITAL MEDICAL RECORD INCLUDES THE PATIENT'S NAME, ADDRESS, AGE, NEXT OF KIN, NAMES OF PARENTS, DATE AND PLACE OF BIRTH, MARITAL STATUS, RELIGION, MILITARY SERVICE, SOCIAL SECURITY OR MEDICARE NUMBER, SOURCE OF REIMBURSEMENT COVERAGE (INSURANCE OR GOVERNMENTAL), AND THE IDENTIFICATION NUMBER ASSIGNED BY THE HOSPITAL.

THE MEDICAL HISTORY INCLUDES THE CHIEF COMPLAINT, DETAILS OF PRESENT ILLNESS, PAST MEDICAL, SOCIAL AND FAMILY HISTORIES, PREVIOUS TREATMENT, AN INVENTORY OF HISTORY RELATED TO EACH BODY SYSTEM, MEDICATIONS TAKEN IN THE PAST AND AT PRESENT, USE OF ALCOHOL AND TOBACCO, PRENATAL HISTORY IF AN OBSTETRICAL PATIENT, AND THE PROVISIONAL DIAGNOSIS.

THE PHYSICAL EXAMINATION RECORD CONTAINS POSITIVE AND NEGATIVE FINDINGS OF A COMPREHENSIVE CURRENT PHYSICAL ASSESSMENT AND A PRELIMINARY DIAGNOSIS.

THE RECORD CONTAINS BY DATE AND IDENTIFICATION OF THE RECORDER, ALL FINDINGS OF DIAGNOSTIC TESTS ADMINISTERED, CONSULTATIONS SOUGHT AND RENDERED, ALL ORDERS FOR MEDICATIONS AND TREATMENTS, ALL TREATMENTS PROVIDED, DRUGS ADMINISTERED, FINDINGS, OBSERVATIONS, PROGRESS, REACTIONS OR INCIDENTS. FINALLY, THERE IS A COMPREHENSIVE SUMMARY WRITTEN AT THE TIME OF DISCHARGE.

STANDARDS FOR MEDICAL RECORDS ARE ESTABLISHED AND ENFORCED BY THE JOINT COMMISSION ON THE ACCREDITATION OF HOSPITALS AND BY DHEW FOR FEDERAL HEALTH PROGRAMS.

CONTENT OF RECORDS - AFFECT OF NON-MEDICAL USES

THE AMOUNT OF DETAIL RECORDED IN THE MEDICAL RECORD MAY BE AFFECTED BY THE KNOWLEDGE ON THE PART OF THE PATIENT, MEMBERS OF THE FAMILY, OR THE PHYSICIAN AND OTHER HEALTH CARE PRACTITIONERS ABOUT ITS POSSIBLE USES.

PATIENTS WHO ARE AWARE THAT THE INFORMATION IN THE RECORD MAY BE AVAILABLE TO THIRD PARTY PAYORS, ATTORNEYS, EMPLOYERS, LIFE INSURANCE COMPANIES OR OTHERS MAY WITHHOLD CERTAIN INFORMATION THAT HE BELIEVES CAN BE USED AGAINST HIM OR THAT HE CONSIDERS TO BE OF SUCH A PERSONAL NATURE THAT ITS DISCLOSURE MIGHT BE EMBARRASSING. SIMILARLY, MEMBERS OF THE PATIENT'S FAMILY MAY NOT WISH TO MAKE FULL DISCLOSURE FOR THE SAME REASONS. THIS IS PARTICULARLY TRUE WITH REGARD TO FAMILY HISTORY, INTERPERSONAL PROBLEMS, USE OF ALCOHOL AND DRUGS, AND SIMILAR QUESTIONS THAT MAY BE ASKED ABOUT IN CONNECTION WITH A POSSIBLE MENTAL ILLNESS. THIS SITUATION IS OF GROWING CONCERN TO PHYSICIANS WHO FEAR THAT THE DEMANDS FOR MEDICAL INFORMATION FOR PURPOSES OTHER THAN CARE OF THE PATIENT HAS RESULTED IN CONCEALMENT OF IMPORTANT INFORMATION HAVING DIRECT BEARING ON THEIR ABILITY TO DIAGNOSE AND TREAT THE PATIENT.

RELEVANT TO THE SECONDARY USERS CITED PREVIOUSLY, INCREASED DISSEMINATION OF MEDICAL RECORDS AND INFORMATION, EVEN THOUGH MOST INFORMATION IS RELEASED WITH CONSENT OF THE PATIENT, HAS RESULTED IN ABUSES OF CONFIDENTIALITY AND THE EMERGENCE OF PRIVACY AS A PUBLIC ISSUE. THE PRIVACY ACT PASSED BY CONGRESS IN 1974 CREATED THE PRIVACY PROTECTION STUDY COMMISSION. THE COMMISSION REPORT RELATIVE TO MEDICAL RECORDS CONCLUDED THAT "MEDICAL RECORDS CONTAIN MORE INFORMATION, ARE MORE AVAILABLE TO MORE USERS, ARE LESS WELL-CONTROLLED AND ARE USED FOR MORE NON-MEDICAL PURPOSES THAN EVER BEFORE." THIS REPORT WAS SUBMITTED IN JULY 1977 - AND I ASSURE

YOU THAT THE CONDITIONS RELEVANT TO MEDICAL RECORD PRIVACY HAVE ONLY INTENSIFIED SINCE THEN.

CASES OF ABUSE RESULTING FROM ACCESS TO MEDICAL RECORDS AND MEDICAL INFORMATION ARE WELL-DOCUMENTED. PERHAPS THE BEST KNOWN CRIMINAL CASES ARE THE ELLSBERG CASE AND THE RECENT DENVER CASE, IN WHICH PRIVATE INVESTIGATIVE FIRMS HIRED BY INSURANCE COMPANIES POSED AS MEDICAL PROFESSIONALS AND OBTAINED MEDICAL RECORDS UNDER FALSE PRETENSES FROM HOSPITALS. OTHER SAMPLE CASES OF MISUSE OR MIS-HANDLING OF MEDICAL INFORMATION INCLUDES TRANSFER OF DIAGNOSES FROM THE INSURANCE COMPANY TO PATIENTS' EMPLOYERS, TRANSFER OF INFORMATION ON A HUSBAND OR WIFE WHO HAS BEEN A PATIENT VIA THE INSURANCE COMPANY AND/OR EMPLOYER, LINKAGE OF MEDICAL WITH NON-MEDICAL COMPUTER FILES IN THE NAME OF RESEARCH, USE OF MEDICAL INFORMATION IN DENYING INSURANCE, EMPLOYMENT, AND SO ON.

PATIENT ACCESS AND RECORD CORRECTION

THE PRIVACY COMMISSION REPORT STATES TWO IMPORTANT CONCLUSIONS REGARDING PATIENT ACCESS AND AUTHORIZATION FOR RELEASE OF MEDICAL RECORDS. FIRST, IN SPITE OF THE INCREASED USES AND USERS OF PATIENT HEALTH INFORMATION IT IS RARE FOR THE PATIENT TO HAVE DIRECT ACCESS TO MEDICAL INFORMATION AND TO REVIEW IT FOR ACCURACY, OR TO CONTROL THE DISCLOSURE OF INFORMATION. AND, IN MANY INSTANCES, PATIENT AUTHORIZATION TO RELEASE INFORMATION MAY NOT BE CONSENT FREELY GIVEN, WHEN THE PATIENT'S CHOICE MAY BE TO CONSENT OR TO FOREGO EMPLOYMENT, INSURANCE, OR OTHER BENEFITS.

TRADITIONALLY, IT HAS NOT BEEN THE PRACTICE OF HEALTH CARE PROVIDERS OR INSTITUTIONS TO PROVIDE THE PATIENT ACCESS TO THE MEDICAL RECORD ITSELF. IN THE LAST FEW YEARS SOME FOURTEEN (14) STATES HAVE MADE STATUTORY PROVISIONS FOR SUCH ACCESS. IT HAS BEEN THE PRACTICE TO GIVE VERBAL INFORMATION ABOUT FACTS HE SHOULD HAVE OR TO PROVIDE CERTAIN SUMMARY DATA TO THE PATIENT AND THESE PRACTICES SEEM LIKELY TO INCREASE WITH THE GROWING RECOGNITION OF THE INDIVIDUAL'S RIGHT TO KNOW.

THE AMERICAN MEDICAL RECORD ASSOCIATION SUPPORTS THE RIGHT OF THE PATIENT TO HAVE ACCESS TO HIS MEDICAL RECORD. IN AN ERA WHEN THE MEDICAL RECORD IS WIDELY REVIEWED WE BELIEVE THE PATIENT, TOO, DESERVES THIS RIGHT AND THAT SUCH A RIGHT IS NECESSARY FOR THE PATIENT TO BE TRULY INFORMED WHEN HE SIGNS AN AUTHORIZATION FOR RELEASE OF THE MEDICAL RECORD. AMRA'S "MODEL POLICY" ON PATIENT ACCESS READS:

SUBJECT ONLY TO SPECIFIC CONTRAINDICATIONS BY THE ATTENDING PHYSICIAN AND TO ANY LEGAL CONSTRAINTS SUCH AS THOSE GOVERNING MINORS AND THOSE ADJUDICATED AS INCOMPETENT, A PATIENT MAY HAVE ACCESS TO HIS OWN HEALTH RECORD FOR REVIEW UPON WRITTEN REQUEST WITH REASONABLE NOTICE. A PATIENT MAY HAVE ACCESS TO RECORDS OF HIS CARE AFTER DISCHARGE AND COMPLETION OF THE HEALTH RECORD. PHOTOCOPIES OF HEALTH RECORD WILL BE PROVIDED ON WRITTEN REQUEST BY THE PATIENT AND PAYMENT OF A REASONABLE FEE.

AS TO THE CONSEQUENCES, NEGATIVE OR POSITIVE, OF PERMITTING PATIENTS ACCESS TO THEIR MEDICAL RECORDS, THIS IS ALMOST IMPOSSIBLE TO ASSESS BECAUSE OF THE ABSENCE OF ANY BUT THE MOST LIMITED EXPERIENCE. IN STATES WHERE SUCH ACCESS IS AUTHORIZED, AND A PATIENT DEMANDED TO SEE HIS RECORD, IT HAS BEEN CUSTOMARY TO HAVE THE RECORD REVIEWED IN THE PRESENCE OF A PHYSICIAN.

CERTAIN LIMITED EXPERIENCES WERE REPORTED AND DISCUSSED IN A MEETING ON CONFIDENTIALITY HELD IN 1974. IT WAS CITED THAT REVIEW OF THE RECORD BY THE SUBJECT OR MEMBER OF THE FAMILY RESULTED IN STRESS AND TRAUMA ON THE PART OF THE REVIEWER. OTHER EXPERIENCES WERE REPORTED AS FAVORABLE, WITH THE PATIENT BECOMING MORE COOPERATIVE BECAUSE OF HIS INCREASED UNDERSTANDING OF HIS OWN MEDICAL CONDITION. ONE STUDY INVOLVED SHARING THE ADMISSION NOTES AND EVENTUALLY HIS PROBLEM ORIENTED RECORD. IT WAS STATED THAT MOST PATIENTS REACTED POSITIVELY, COULD HANDLE THE INFORMATION, AND DISCUSSION BETWEEN STAFF AND PATIENT WAS EXPEDITED. THE CONCLUSION WAS THAT MEDICAL INFORMATION SHARING IS A TOOL THAT MAY IMPROVE PATIENTS' SATISFACTION WITH THEIR CARE.

STATES IN WHICH PATIENT ACCESS LEGISLATION HAS BEEN PASSED IN RECENT YEARS, HAVE REPORTED NO GREAT DEMAND FOR RECORDS AS A RESULT. PERHAPS THIS IS DUE TO LACK OF INTEREST ON THE PART OF PATIENTS OR PERHAPS PATIENTS ARE NOT AWARE THAT THEY MAY HAVE ACCESS. REGARDLESS, WE SUPPORT THE OPPORTUNITY FOR PATIENT ACCESS.

BECAUSE OF THE EXTREMELY LIMITED EXPERIENCE WITH PERMITTING PATIENTS ACCESS TO THEIR RECORDS, IT IS NOT POSSIBLE TO COMMENT ON ITS IMPACT ON MALPRACTICE SUITS EITHER FAVORABLY OR UNFAVORABLY. IF SUCH ACCESS WERE TO BECOME GENERAL PRACTICE, ONE COULD MAKE CERTAIN GUESSES AS TO THE IMPACT. IT IS KNOWN THAT SOME MALPRACTICE SUITS ARE BASED ON ERRONEOUS CONCLUSIONS

REACHED BY THE PATIENT THAT WOULD BE CORRECTED BY READING THE ACTUAL RECORD. TO THE EXTENT THAT MISINFORMATION IS CORRECTED, SOME MALPRACTICE SUITS MIGHT BE PREVENTED.

ONE CAN ALSO CONCLUDE THAT ADVANCE AWARENESS ON THE PART OF THOSE WHO MAKE ENTRIES IN THE RECORD THAT THE PATIENTS MAY READ THE RECORD ON REQUEST WILL RESULT IN MORE CAREFUL RECORDING SO THAT MISINTERPRETATIONS CAN BE AVOIDED. CERTAINLY, THE RECORDING OF INFORMATION PROVIDED BY THE PATIENT WILL BE DONE WITH CARE, AND OPPORTUNITIES AFFORDED FOR OFFICIAL CORRECTION OF THIS INFORMATION SHOULD AN ERROR INADVERTENTLY OCCUR.

CORRECTIONS

AT PRESENT, CORRECTIONS ARE MADE IN THE RECORD, AS ARE ENTRIES THEMSELVES, BY MEMBERS OF THE HEALTH PROFESSIONS, UNDER GUIDELINES ESTABLISHED BY THE INSTITUTION. ALL ENTRIES MUST BE DATED AND AUTHENTICATED BY THE RECORDER. WHEN AN ERROR IS DISCOVERED, IT IS LINED THROUGH AND SIGNED BY THE AUTHOR WITH THE CORRECT INFORMATION ADDED.

PROVISION OF ACCESS AND CORRECTION BY THE RECORD SUBJECT DOES NOT GENERALLY VIOLATE THE CONFIDENTIALITY OF THE DOCTOR/PATIENT RELATIONSHIP. HOWEVER, IT MUST BE REMEMBERED THAT WHENEVER A PHYSICIAN OR OTHER HEALTH PROFESSIONAL OBTAINS CONFIDENTIAL INFORMATION FROM A FAMILY MEMBER OR OTHER CONFIDANT AND ENTERS THE INFORMATION IN THE RECORD TO WHICH THE PATIENT HAS ACCESS, THERE MAY BE A VIOLATION OF THE CONFIDENTIAL NATURE OF THAT INFORMATION. THIS IS OF EXTREME IMPORTANCE IN PSYCHIATRIC RECORDS IN WHICH INFORMATION SECURED FROM OTHERS ABOUT A PATIENT'S BEHAVIOR, FAMILY ATTITUDES, AND THE LIKE ARE IMPORTANT TO UNDERSTANDING THE PATIENT'S PROBLEMS BUT CAN BE DAMAGING IF DISCLOSED TO THE PATIENT.

THE EXTENT TO WHICH THE DOCTOR/PATIENT RELATIONS MIGHT BE ALTERED IS DIFFICULT TO ASSESS. THERE IS NO AGREEMENT AMONG PHYSICIANS THAT PATIENT ACCESS TO THE RECORD SHOULD BE PERMITTED. SUCH A PRACTICE IS CONTRARY TO THEIR ENTIRE PROFESSIONAL TRAINING AND EXPERIENCE. THEY BELIEVE IT IS THEIR RIGHT AND PRIVILEGE TO INTERPRET TO THE PATIENT AND/OR HIS FAMILY WHAT THEY BELIEVE THEY SHOULD KNOW. THERE ARE STRONG VIEWS ABOUT THE RIGHT OF THE PATIENT TO HAVE EARLY KNOWLEDGE OF CERTAIN OR POTENTIALLY FATAL ILLNESS. THIS, MANY PHYSICIANS BELIEVE, IS A MATTER THAT MUST BE DETERMINED IN EACH INDIVIDUAL'S SITUATION.

BECAUSE OF THE ESPECIALLY SENSITIVE NATURE OF CERTAIN KINDS OF RECORDS, IT WOULD BE NECESSARY TO ESTABLISH SPECIAL PROCEDURES AND SAFEGUARDS, FOR EXAMPLE, RECORDS OF PSYCHIATRIC ILLNESS, ABORTIONS, ALCOHOLISM AND OTHER DRUG ADDICTIONS.

A PROBLEM CONCERNING ACCESS TO THE MEDICAL RECORDS OF FORMER PATIENTS THAT SHOULD BE MENTIONED IS THAT OF IDENTIFICATION OF THE PERSON SEEKING ACCESS. IT HAS BEEN WELL DOCUMENTED THAT ALMOST ANYONE CAN SECURE FALSE IDENTIFICATION PAPERS WITH FRIGHTENING EASE. A FALSELY IDENTIFIED DRIVER'S LICENSE, SOCIAL SECURITY CARD, OR EVEN A PASSPORT IS NOT DIFFICULT TO SECURE. HOW TO ASSURE THAT THE PERSON CLAIMING TO BE A FORMER PATIENT IS IN FACT THAT PATIENT POSES SERIOUS PROBLEMS TO MEDICAL RECORD PRACTITIONERS IN WHOSE CUSTODY AND TRUST MEDICAL RECORDS ARE PLACED. AMRA POSITION STATEMENT RECOMMENDS "CONTINUED DEVELOPMENT OF STATE AND FEDERAL LEGISLATION TO IMPOSE PENALITIES OF FIVE AND/OR IMPRISONMENT" FOR OBTAINING MEDICAL RECORDS UNDER FALSE PRETENSES OR MISUSE OF MEDICAL INFORMATION.

RESEARCH

AMRA BELIEVES THAT MEDICAL RECORDS, SHOULD BE MADE AVAILABLE FOR RESEARCH TO INDIVIDUALS WHO HAVE HAD PROJECTS APPROVED BY APPROPRIATE INSTITUTIONAL BOARDS AND AUTHORITIES. DATA COMPILED AS A PART OF RESEARCH PROJECTS MAY NOT INCLUDE PATIENT IDENTITY WITHOUT CONSENT OF THE PATIENT.

THOSE WHO CONDUCT BONAFIDE RESEARCH PROJECTS SHOULD BE BOUND TO PRESERVE THE CONFIDENTIALITY OF PERSONALLY IDENTIFIABLE INFORMATION, AND MAY DISCLOSE INFORMATION ONLY IN THE FORM OF AGGREGATE DATA. EVIDENCE THAT THE DATA COULD BE USED ONLY IN THIS MANNER SHOULD BE REQUIRED BEFORE RECORDS ARE RELEASED TO RESEARCH STAFF. HOWEVER, THIS SUBJECT SHOULD BE SPECIFICALLY ADDRESSED AND APPROPRIATE PROVISIONS MADE IN ANY LEGISLATION ON PRIVACY OF MEDICAL INFORMATION.

AUTHORIZATIONS

THE MAJORITY OF RELEASES OF MEDICAL RECORDS ARE MADE ONLY AFTER THE PATIENT HAS SIGNED AN AUTHORIZATION FOR RELEASE OF SUCH INFORMATION. HOWEVER, A MAJOR PROBLEM IN THE CONFIDENTIALITY QUESTION IS THE FORMAT AND METHODOLOGY OF SUCH AUTHORIZATIONS OR CONSENTS SIGNED BY THE PATIENT. THERE ARE THREE TYPES OF CONSENTS WHICH POSE A PROBLEM: THE "BLANKET CONSENT," THE "PROSPECTIVE CONSENT," AND THE "PERPETUAL CONSENT."

FIRST, IN "BLANKET CONSENT," PATIENTS OR GUARDIANS ARE ASKED TO SIGN RELEASES WHICH ALLOW FACILITIES TO DISSEMINATE "ANY AND ALL" IDENTIFIABLE INFORMATION TO WHOMEVER IS OFFERING A BENEFIT OR SERVICE TO THE PATIENT. THE PATIENT IS NOT HIMSELF "INFORMED" AS TO THE FULL EXTENT OF THE RECORD'S CONTENT, WHICH SEGMENTS OF IT WILL BE OPEN TO THIRD PARTY ACCESS, OR WHAT WILL HAPPEN TO THE INFORMATION ONCE IT IS IN THE THIRD PARTY'S POSSESSION. "BLANKET CONSENT" DOES NOT SERVE TO INSTILL A SENSE OF RESPONSIBILITY IN THE COLLECTORS, STORERS AND USERS OF PATIENT DATA.

SECOND, DIFFICULTY ARISES FROM THE COMMON THIRD PARTY PRACTICE OF REQUESTING "PROSPECTIVE CONSENT," OR CONSENT OF RELEASE OF INFORMATION PRIOR TO TREATMENT. THIS MEANS THAT THE PATIENT IS CONSENTING TO THE DISSEMINATION OF THAT WHICH IS NOT YET COLLECTED, A PRACTICE WHICH PRECLUDES ANY INTELLIGENT DECISION-MAKING ON THE PART OF THE PATIENT.

THIRD, MOST INSURANCE COMPANIES REQUEST A FORM OF CONSENT WHICH COULD BE CONSTRUED AS "PERPETUAL CONSENT," SINCE THERE IS NO ATTENDANT TIME LIMIT SET FOR VALIDITY OF THE CONSENT. WITH OTHER REQUESTORS, HEALTH CARE INSTITUTIONS VARY IN THE TIME LIMITS WITHIN WHICH THEY ACCEPT PATIENT CONSENT AS "CURRENT."

IN SOME CASES HEALTH CARE INSTITUTIONS ARE ADOPTING MORE STRINGENT LIMITS, BUT THERE IS NO UNIFORMITY OF POLICY IN THIS AREA.

THE MOST FREQUENT DISCLOSURE OF MEDICAL RECORD INFORMATION IS TO THIRD PARTY PAYORS: BLUE CROSS, BLUE SHIELD, COMMERCIAL INSURANCE CARRIERS, AND FEDERAL AND STATE GOVERNMENTS WHETHER DIRECTLY OR THROUGH FISCAL INTER-MEDIARIES, FOR REIMBURSEMENT OR CLAIMS PURPOSES.

THE AMOUNT OF INFORMATION PROVIDED IS USUALLY DETERMINED IN RELATION TO THE PURPOSE AND TO THE SCOPE OF AUTHORIZATION. THE DEMANDS OF THIRD PARTY PAYORS WERE, IN THE PAST, REASONABLY LIMITED. INCREASINGLY DURING THE PAST SEVERAL YEARS, DEMANDS FOR MORE EXTENSIVE DOCUMENTATION IN CONNECTION WITH CLAIMS PROCESSING HAVE EXPANDED TO INCLUDE COPIES OF DISCHARGE SUMMARIES OR, MORE AND MORE FREQUENTLY ESPECIALLY FOR MEDICARE OR MEDICAID REIMBURSEMENT, PHOTOCOPIES OF THE ENTIRE RECORD. THIS PRESENTS A COSTLY AND TIME CONSUMING DEMAND AND THE EXTENSIVE DISCLOSURE INVOLVED IS DISTURBING TO MEDICAL RECORD PRACTITIONERS IN LIGHT OF THEIR ETHICAL RESPONSIBILITIES.

WE BELIEVE THAT THE PRACTICE OF COPYING ENTIRE MEDICAL RECORDS FOR REVIEW OUTSIDE HOSPITAL PREMISES IS A PRACTICE LARGELY FOR THE "CONVENIENCE" OF FISCAL INTERMEDIARIES, INSURANCE COMPANIES, PSRO'S, ETC. AMRA HAS VOICED ITS OPPOSITION TO THIS PRACTICE TO NO AVAIL.

THE MEDICAL RECORD PRACTITIONER IS EXPECTED BY THE ADMINISTRATION AND THE MEDICAL STAFF TO USE DISCRETION IN THE AMOUNT AND KIND OF INFORMATION RELEASED AND TO REQUIRE ASSURANCE IN THE FORM OF WRITTEN AUTHORIZATION TO DISCLOSE. THIS RESPONSIBILITY PLACES THE MEDICAL RECORD PRACTITIONER IN THE ALMOST IMPOSSIBLE POSITION OF TRYING TO DETERMINE, WITH RESPECT TO THE RELEASE OF MEDICAL INFORMATION ABOUT AN INDIVIDUAL, WHETHER THAT INDIVIDUAL WAS AWARE OF THE FULL IMPLICATIONS OF THE INFORMATION THAT MIGHT BE DISCLOSED

OR HOW IT MIGHT BE USED WHEN HE SIGNED THE AUTHORIZATION FORM. THIS DILEMMA STEMS FROM THE ABSENCE OF SPECIFICITY IN AUTHORIZATION FORMS.

MEDICAL RECORD PRACTITIONERS WOULD BE RELIEVED OF THE BURDEN OF TRYING TO DECIDE WHAT IS APPROPRIATE TO INCLUDE IN A REPORT DISCLOSING PERSONAL HEALTH INFORMATION IF THERE WERE A CAREFULLY DESIGNED, UNIVERSALLY ACCEPTED AND MANDATED GUIDELINES FOR AUTHORIZATION OF RELEASE OF MEDICAL INFORMATION FORM THAT PERMITS THE INDIVIDUAL TO HAVE FULL KNOWLEDGE ABOUT THE EXTENT TO THE DISCLOSURE AND THE USES TO WHICH THE INFORMATION WILL BE PUT SO THAT HE CAN GIVE AN INFORMED CONSENT.

THE AMERICAN MEDICAL RECORD ASSOCIATION'S POSITION STATEMENT INCLUDES THE FOLLOWING MODEL POLICY ON AUTHORIZATIONS:

ALL INFORMATION CONTAINED IN THE HEALTH RECORD IS CONFIDENTIAL AND THE RELEASE OF INFORMATION WILL BE CLOSELY CONTROLLED. A PROPERLY COMPLETED AND SIGNED AUTHORIZATION IS REQUIRED FOR RELEASE OF ALL HEALTH INFORMATION EXCEPT:

- A. AS REQUIRED BY LAW
- B. FOR RELEASE TO ANOTHER HEALTH CARE PROVIDER CURRENTLY INVOLVED IN THE CARE OF THE PATIENT
- C. FOR MEDICAL CARE EVALUATION
- D. FOR RESEARCH AND EDUCATION

IN KEEPING WITH THE TENET OF INFORMED CONSENT, A PROPERLY COMPLETED AND SIGNED AUTHORIZATION TO RELEASE PATIENT INFORMATION SHALL INCLUDE AT LEAST THE FOLLOWING DATA:

- A. NAME OF INSTITUTION THAT IS TO RELEASE THE INFORMATION
- B. NAME OF INDIVIDUAL OR INSTITUTION THAT IS TO RECEIVE THE INFORMATION
- C. PATIENT'S FULL NAME, ADDRESS AND DATE OF BIRTH

- D. PURPOSE OR NEED FOR INFORMATION
- E. EXTENT OR NATURE OF INFORMATION TO BE RELEASES, INCLUDING
INCLUSIVE DATES OF TREATMENT - NOTE: AN AUTHORIZATION SPECIFYING
"ANY AND ALL INFORMATION ..." SHALL NOT BE HONORED
- F. SPECIFIC DATE, EXENT OR CONDITION UPON WHICH CONSENT WILL EXPIRE
UNLESS REVOKED EARLIER
- G. STATEMENT THAT CONSENT CAN BE REVOKED BUT NOT RETROACTIVE TO THE
RELEASE OF INFORMATION MADE IN GOOD FAITH
- H. DATE THAT CONSENT IS SIGNED - NOTE: DATE OF SIGNATURE MUST BE
LATER THAN THE DATES OF INFORMATION TO BE RELEASED
- I. SIGNATURE OF PATIENT OR LEGAL REPRESENTATIVE

WE BELIEVE THAT LEGISLATION WHICH PROVIDES STRICT PROVISIONS FOR
AUTHORIZATIONS WILL BE A GREAT ASSET TO LIMITING DISCLOSURE OF INFORMATION,
ESPECIALLY COPYING AND DISSIMINATING ENTIRE COPIES OF MEDICAL RECORDS. WE
CAUTION CONGRESS, HOWEVER, NOT TO PLACE THE SOLE PROVISION FOR PROPER
AUTHORIZATION IN A MEDICAL RECORD PRIVACY ACT. RESPONSIBILITY SHOULD ALSO
BE PLACED ON THE INSURANCE INDUSTRY THROUGH LEGISLATION ON INSURANCE PRIVACY.
SUCH RESPONSIBILITY INCLUDES THE MEDICARE/MEDICAID AND OTHER FEDERAL INSURANCE
PROGRAMS AS WELL AS PRIVATE CARRIERS.

DISCLOSURE WITHOUT AUTHORIZATION

RELEASE OF MEDICAL RECORDS WITHOUT A SIGNED AUTHORIZATION IS CONSIDERED A LEGITIMATE PRACTICE UNDER SEVERAL INSTANCES: RELEASE TO HEALTH EMPLOYEES AND CONSULTANTS, FOR HEALTH RESEARCH, AUDITS AND EVALUATIONS, PUBLIC HEALTH AND SAFETY, LAW ENFORCEMENT, JUDICIAL AND ADMINISTRATIVE PROCEEDINGS AND PER SUBPOENA, SUMMONS, OR SEARCH WARRANTS.

IT IS DOUBTFUL THAT ANY USEFUL PURPOSE WOULD BE SERVED BY MANDATING THE ROUTINE NOTIFICATION TO THE SUBJECT OF ALL RELEASE OF INFORMATION IN ANY AND ALL CIRCUMSTANCES, THE COST OF DOING SO, INCLUDING THE COST OF PERSONNEL TIME, WOULD BE SUBSTANTIAL, AND THE WORK LOAD IN A BUSY MEDICAL RECORD DEPARTMENT IS SUCH AS TO MAKE DIFFICULT, IF NOT IMPOSSIBLE, THE PREPARATION AND MAILING OF SUCH NOTICES IN A TIMELY MANNER. ANY REQUIREMENT FOR PROVISION OF NOTICE TO THE SUBJECT MIGHT BETTER BE PLACED ON THE AGENCY, PERSON, OR COURT REQUESTING OR ORDERING THE INFORMATION IN THOSE CIRCUMSTANCES IN WHICH THE SUBJECT DOES NOT SIGN A SPECIFIC CONSENT TO RELEASE FROM. THE HEALTH FACILITY SHOULD INFORM THE PATIENT OF REGARDING CIRCUMSTANCES IN WHICH HIS MEDICAL RECORDS WILL BE RELEASED WITHOUT HIS AUTHORIZATION, HOWEVER.

ALSO, ANY LEGISLATION SHOULD STATE EXPLICIT CIRCUMSTANCES UNDER WHICH MEDICAL RECORDS CAN BE OBTAINED WITHOUT AUTHORIZATION ANY SHOULD PROVIDE SAFEGUARDS TO PREVENT DIRECT OR INDIRECT IDENTIFICATION OF PATIENTS OR FURTHER DISCLOSURE FROM THOSE RECEIVING RECORDS.

COMPUTERIZED DATA

THE HEALTH INDUSTRY IS ACUTELY AWARE OF THE INSIDIOUS EROSION OF CONFIDENTIALITY BROUGHT ON BY GROWING DEMANDS FOR MEDICAL INFORMATION. INFORMATION TRANSFER IS STAGGERING AND EXPENSIVE. TO MEET THE DEMANDS AND NEEDS FOR INFORMATION, HEALTH CARE FACILITIES AND RECIPIENTS OF INFORMATION HAVE TURNED TO COMPUTERIZED SYSTEMS.

INFINITE STORAGE CAPACITY AND LINKAGE ABILITY BETWEEN COMPUTERIZED TECHNOLOGIES HAS DEALT THE GREATEST BLOW TO CONFIDENTIALITY. MASSIVE NATIONWIDE DATA SYSTEMS ARE OPERATED BY BLUE CROSS/BLUE SHIELD, MEDICARE, DHEW, PSRO'S, PRIVATE INSURANCE CARRIERS AND INSURANCE SERVICE FIRMS SUCH AS THE MEDICAL INFORMATION BUREAU AND EQUIFAX. THESE SYSTEMS NOT ONLY HAVE THE CAPACITY TO LINK DATA BUT ARE ACTIVE IN THIS ENDEAVOR. PERHAPS THE MOST FRIGHTENING ASPECT OF COMPUTERIZATION IN HEALTH TODAY IS ACTIVITY SUPPORTED BY CONGRESS THROUGH PASSAGE OF PUBLIC LAW 95-142 MEDICARE/MEDICAID ANTI-FRAUD AND ABUSE AMENDMENTS OF 1977, SECTION 19, AND UNDER THE JURISDICTION OF THE DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE'S HEALTH CARE FINANCING ADMINISTRATION. DHEW WILL SOON ISSUE PROPOSED REGULATIONS WHICH CALL FOR THE COLLECTION OF A UNIFORM HOSPITAL DISCHARGE DATA SET (UHDDS) WHICH INVOLVES PATIENT AND PROVIDER IDENTITIES, DIAGNOSES, ETC. THE UHDDS WILL BE COLLECTED AND PROCESSED BY REGIONAL PROCESSORS, WHICH MAY INCLUDE FISCAL INTERMEDIARIES, MEDICAL RECORD DISCHARGE ABSTRACT PROCESSES, PSRO'S, AND INSURANCE COMPANIES. IDENTIFIABLE DATA WILL BE LINKED TO BILLING DATA AND STORED IN A NATIONAL DATA BANK IN THE DHEW. DATA WILL BE DISTRIBUTED TO PSRO'S, HSA'S, AND OTHER FEDERAL DEPARTMENTS. THE NATIONAL HEALTH COMPUTER BANK WHICH WE WERE TOLD WOULD NEVER BE CREATED IS HERE. THERE IS NO REASON TO BELIEVE THAT AT SOME FUTURE DATE THIS HEALTH DATA WILL NOT BE

LINKED TO FBI, CIA, IRS, CREDIT, INSURANCE AND OTHER COMPUTERS. AMRA HAS VOICED STRONG OPPOSITION TO DHEW PLANS FOR DATA COLLECTION AND WE AWAIT PROPOSED REGULATIONS.

ANY NATIONAL HEALTH INSURANCE (NHI) PROGRAM IS LIKELY TO EXPAND REPORTING REQUIREMENTS AND CENTRALIZE THE INFORMATION COLLECTED IN DATA BANKS. THE PROTECTION OF THESE CENTRALIZED RECORDS AGAINST IMPROPER DISCLOSURE AND USE BECOMES THE RESPONSIBILITY OF THOSE WHO MAINTAIN THE DATA BANKS. UNFORTUNATELY, IT IS KNOWN THAT CODES CAN BE BROKEN AND THAT THERE APPEARS TO BE NO KNOWN ABSOLUTE SAFEGUARD AGAINST UNLAWFUL ACCESS TO COMPUTER-STORED INFORMATION.

LEGISLATION CREATED THE AUTHORITY FOR CURRENT COMPUTER ACTIVITY. ANY LEGISLATION ON DATA SECURITY MUST FIRST PUT LIMITS ON DATA COLLECTED AND PLACE STRINGENT RESTRICTIONS ON RELEASE AND LINKAGE.

SUMMARY

THE MEDICAL RECORD PRACTITIONERS, HEALTH PROVIDERS AND PATIENTS ARE IN A SERIOUS DILEMMA OVER CONFIDENTIALITY. THE DILEMMA OF THE MEDICAL RECORD PROFESSION CENTERS ON HOW TO FULFILL THE OBLIGATIONS TO PROVIDE NEEDED INFORMATION TO SERVE THE PATIENT, PROVIDER, AND THE COMMUNITY WHILE PROTECTING THE PATIENT. THE DILEMMA FOR THE HEALTH PROVIDER IS CONFIDENTIALITY VS. PAYMENT FOR SERVICES ON A TIMELY BASIS TO ASSURE CASH FLOW. THE DILEMMA FOR THE PATIENT IS CONFIDENTIALITY VS. INSURANCE, EMPLOYMENT, CREDIT AND OTHER SERVICES. IN REALITY, THE QUESTION COMES DOWN TO CONFIDENTIALITY VS. MONEY!

IN SUMMARY, THE AMERICAN MEDICAL RECORD ASSOCIATION STRONGLY SUGGESTS VOLUNTARY AND LEGISLATIVE EFFORTS:

- * TO PROVIDE PATIENT ACCESS TO MEDICAL RECORDS WITH PROPER RESTRICTIONS
- * TO ASSURE THE PATIENT FULL KNOWLEDGE OF AND CONTROL OVER DISSIMINATION OF HIS PRIVATE INFORMATION THROUGH STRICT AUTHORIZATION FOR RELEASE OF INFORMATION
- * TO CONTROL RE-DISCLOSURE BY SECONDARY RECIPIENTS AND USERS OF MEDICAL INFORMATION
- * TO CONTROL LINKAGE OF COMPUTERIZED HEALTH INFORMATION SYSTEMS.

IN CONCLUSION, I QUOTE FROM COMPUTERS, HEALTH RECORDS, AND CITIZENS RIGHTS A STUDY CONDUCTED UNDER THE INSTITUTE FOR COMPUTER SCIENCES OF THE NATIONAL BUREAU OF STANDARDS, BY ALAN WESTIN, "AS AMERICAN SOCIETY REDEFINES AND REORGANIZES ITS HEALTH-CARE SYSTEM IN THE COMING DECADE, IT WILL HAVE TO MAKE INCREASED USE OF COMPUTER TECHNOLOGY TO MANAGE THE RIVERS OF DATA THAT WILL BE GENERATED ... IF THE QUESTION IS NOT WHETHER BUT HOW SUCH TECHNOLOGY WILL BE USED IN HEALTH CARE, AMERICAN SOCIETY HAS ONE NONNEGOTIABLE CONDITION FOR THIS PROCESS: BASIC CITIZEN RIGHTS CANNOT BE MADE A CASUALTY OF TECHNOLOGY-ASSISTED HEALTH SYSTEMS. TO DO SO WOULD BE TO BETRAY THE TRADITION OF HIPPOCRATES, AND ULTIMATELY TO DEHUMANIZE HEALTH CARE ITSELF."

Mr. DRINAN. Dr. Jerome Beigler is the Chairman of the American Psychiatric Association Committee on Confidentiality.

We welcome you here, Doctor. You may proceed as you see fit.

STATEMENT OF DR. JEROME S. BEIGLER, CHAIRPERSON, COMMITTEE ON CONFIDENTIALITY, AMERICAN PSYCHIATRIC ASSOCIATION

Dr. BEIGLER. Thank you.

Mr. Chairman, the American Psychiatric Association, a medical specialty society representing over 24,000 psychiatrists nationwide, appreciates the opportunity to testify before your subcommittee on the need for legislative proposals to protect the confidentiality of medical records.

I am Dr. Jerome S. Beigler, chairperson of the Committee on Confidentiality of the American Psychiatric Association, and a member of the executive committee of the National Commission on the Confidentiality of Health Records, a privately funded consortium of 24 national provider and consumer organizations. I am also clinical professor of psychiatry at the University of Chicago Pritzker School of Medicine and president of the Illinois Psychiatric Society.

It is indeed an honor and privilege to appear before this subcommittee to discuss the considerable problems involved in maintaining the confidentiality of medical and psychiatric records in our information-hungry society.

For a society so complex as ours to function optimally, an ambience must be provided for the maximum expression of the talent of our highly-endowed citizenry. As evidenced by the outstanding leadership over the past 200 years in such fields as politics, economics, literature, and science, our democracy, as designed by our Founding Fathers, works better than any other system of government yet devised by man.

To preserve that democracy, the Bill of Rights was added to the Constitution in order to protect American citizens from their own Government. The power of our Constitution to protect our political system has been severely tested during the past two decades, as in the Joe McCarthy problem and the Nixon episode, in which our roots were severely tested, and has proven its worth reassuringly. But the healthy nature of our political process has inherent in it the development of repeated challenges to the roots of our democracy.

One of these important roots is the ability to provide real privacy even in an ever-increasingly information-hungry society. It is in the context of a challenge to the democratic process itself that we see the crucial importance of protecting the confidentiality of medical and particularly psychiatric records.

To avail oneself of psychiatric help, it is necessary that the most intimate and private thoughts be disclosed to the physician. Any interference with the maintenance of confidentiality of such communications impairs the ability of a psychiatrist to help his or her patient. Because the material disclosed to a psychiatrist includes information relevant to a patient's relationships to the whole outside world, the psychiatrist becomes the repository of information valuable to many third parties, such as insurance carriers, legal

adversaries, law enforcement agencies, and employers. To the extent that such information is disclosed without the patient's consent, the reliability of the doctor-patient relationship is eroded and the ability of a physician to help his or her patient is impaired.

It is not commonly understood that in most States there are no laws that effectively protect the confidential information revealed to a psychiatrist. In the past there were few cases in which breaches of confidentiality became significant problems to the patient. As, however, the requirements for more information by insurance carriers, litigants, and Government agencies increased, many complaints were received of intolerable incursions into the privacy of the doctor-patient and particularly the psychiatrist-patient relationship.

It is necessary to draw a new balance between on the one hand society's need to provide an ambience in which stressed patients may be restored or helped to a state of maximum productivity and on the other hand to provide access to information required by a complex society troubled by economic problems, fiduciary immorality, and crime.

I have divided the main problem areas into three specific zones. This has to do with insurance, litigation, and law enforcement. I will try to discuss these in order.

You have already heard in previous testimony about the insurance problems as far as confidentiality is concerned. A common type of problem stemming from breaches of confidentiality regarding medical insurance records occurs when claims for reimbursement are processed through the employers' personnel offices. Several examples are given in the American Psychiatric Association's "Task Force Report 9, June, 1975, Confidentiality and Third Parties," pages 55 to 59, attachment No. 1. I believe there are close to 40 examples of so-called horror stories of breaches of confidentiality, either deliberate or inadvertent, because of the processing of insurance claims.

One example, a hospitalized schizophrenic patient was discharged without being told of the diagnosis because of her fragile state. On return to work she found that her fellow employees knew about the details of her hospitalization. The insurance company had sent a report to the employer. Obviously there had been leaks from the personnel office. The patient became paranoid, resented learning about herself from employees, and terminated treatment to her detriment.

A second patient first learned of her diagnosis from a notice the insurance company sent reporting her bill had been paid. A third patient was assured that no sensitive information from the insurance company would reach the employer. The entire treatment was damaged and the patient became worse when it was learned the employer knew of the treatment and other factors.

Due to problems of the type outlined above, and because psychiatric treatment is still regrettably considered a stigma in our society, many employees do not use their paid for insurance benefits lest their careers be imperiled by being labeled as psychiatric patients. Federal employees, armed services officers, corporate executives, politicians, and teachers often would realistically jeopardize

their careers should their psychiatric treatment be recorded in their personnel file.

There are communities in which teachers are not hired, rehired, tenured, or promoted should it be learned that they are being treated by a psychiatrist. The paradox is that these conscientious teachers who recognize a need for help are discriminated against whereas other teachers who are less insightful have their employment continued and take out their illness on the children.

A specific example, a young man in my own practice was an aide to a prominent Federal employee. He deliberately did not avail himself of his Federal employee's health insurance benefits to underwrite his psychiatric treatment lest some unauthorized person learn of his treatment as the result of the claims processing and then use that information with the patient's superior as a political gambit.

Not only would such a disclosure threaten his job security, but he was of sufficient talent and stature so that he had the potential within 10 to 15 years of himself becoming a national figure and therefore could not hazard such experience for himself.

He was able to pay for his treatment on his own, solved the immediate psychiatric problem, and was free to pursue his promising career. He was able to solve the dilemma of whether or not to use his insurance benefits easily, but others in need of such treatment are less fortunate, and are left with psychiatric problems, chronic distress, and impaired productivity, all to the detriment of society.

I have illustrated above two types of problems resulting from the insurance industry not being able to maintain the confidentiality of claims processing: (1) Actual injuries due to unauthorized disclosures and (2) actual and threatened perils to careers should the fact of psychiatric treatment become known.

The insurance industry often claims it cannot monitor cost-effectiveness of its benefits unless there is complete access to the confidential information transmitted in the psychiatrist-patient relationship. Over the years it has been demonstrated repeatedly that effective monitoring of psychiatric care can be maintained of the Federal employee plan Blue Cross-Blue Shield, Washington, patients via the utilization of a claims form requiring minimal information. It has been demonstrated that it is possible to maintain insurance-benefit cost-control and yet observe confidentiality. Effective methods of maintaining confidentiality are being further tested via peer review pilot studies.

The problem of unauthorized disclosures of confidential information by employer personnel offices can be solved simply by routing insurance benefit claims directly to the insurance carrier's medical director's office, thus bypassing the personnel office. This is already being done successfully in several large corporations.

Employers receive only utilization profiles without identifying information. Personnel and medical records clerks are educated as to the importance of the sensitive material they process and to their obligation to maintain confidentiality. The American Psychiatric Association has devised, as you know, a model State statute on confidentiality—see attachment 2—mandating such protections of privacy. The feasibility of such a model law has already been

demonstrated by having a very similar law already enacted in Illinois, including penalties for breach of confidentiality—see attachment No. 3.

A second major area in which confidentiality problems arise is in matters of litigation, particularly regarding personal injury suits, divorce, and custody cases, and contested insurance claims cases. Because psychiatric treatment depends on the disclosure of sensitive information, a psychiatric patient is particularly vulnerable to the adversarial discovery process should he become involved in litigation.

A specific example is from my own practice. As a matter of fact, this is how I became initiated into this problem. A former patient was hit by a recklessly driven car while she was parked in a parking lot of a supermarket. She sustained a spinal injury and disability. Her lawyer sued for damages, including "pain and suffering."

At that time Illinois' psychiatrist-patient privilege law provided a "patient-litigant exception." Defendant's lawyer correctly and resourcefully claimed that "pain and suffering" constituted having brought "mental condition into issue," thereby waiving the plaintiff's privilege, and my records and testimony were subpoenaed.

The patient had disclosed to me during treatment many intimacies that would be profoundly against her interest should they be disclosed during discovery. Yet the therapeutic disclosures were prerequisite to the considerable success of her treatment, which enabled her to become a contributing, self-supporting, and functional member of society again. The judge refused to limit my testimony only to the issues relevant to the suit. We could resolve the dilemma only by withdrawing the claim for pain and suffering.

It thus became clear that a patient who enters psychiatric treatment automatically jeopardizes future rights to legal redress otherwise available to citizens who had not undertaken such treatment. Subsequently, two Illinois Appellate Court decisions ruled that "pain and suffering" did not constitute "mental condition"—see attachment No. 4—and this provision is included in the cited new Illinois confidentiality law and the cited APA model State law. It would be wise if—and we so recommend—a similar provision were included in Federal legislation.

Another confidentiality and privilege problem arises in divorce and custody cases in States which do not have a no fault divorce law. Should a divorce suit be brought on the ground of "mental cruelty," "mental condition" is considered to have been brought into issue, thereby waiving the psychiatrist-patient privilege and exposing a patient to the hazards of the psychiatrist's testimony.

It becomes apparent that such a privilege law interpretation tends to foster divorce because a sophisticated couple with a marital problem would not seek out counseling to resolve their problem, lest their communications be disclosed during future divorce or custody litigation.

The Illinois legislature wisely recognized the nature of this problem and provided the divorce and custody exception to the patient-litigant exception—see attachment No. 4—in the cited 1979 Illinois confidentiality law and the cited APA model law. A similar proviso is recommended for inclusion in a Federal confidentiality law.

A third privilege law problem as far as litigation is concerned arises when "mental condition" actually is brought into legal issue, thereby waiving privilege for "relevant" testimony. For example, traumatic neurosis or the psychiatric condition itself is made part of the litigation. The question arises in defining "relevant." The issue has been argued in several famous California cases, including "*In re Lifschutz*" and *Caesar v. Mountanos*.

In the latter case Judge Shirley Hufstедler in a dissenting opinion advocated a court-appointed examining psychiatrist testify after examining the patient, thereby relieving the treatment psychiatrist from jeopardizing his therapeutic relationship with the patient. The therapist is called for in camera testimony only if the court-appointed psychiatrist cannot make an adequate assessment.

Testimony from such a court-appointed psychiatrist is the practice in Michigan, and has been incorporated in both previously referred to Illinois confidentiality law and the APA model law. In addition, unique to the Illinois law, it protects the patient from inadvertent or ill-advised waiver of privilege by providing an overriding, limited privilege to the psychiatrist when he exercises it "in the interest of and on behalf of" the patient.

Contested insurance claims also engender medical record confidentiality problems. As you know by now, a multimillion-dollar-a-year industry developed as the result of insurance companies providing a market for unauthorized disclosures of confidential medical information.

A Denver, Colo., State's attorney demonstrated that the Factual Services Bureau was able to furnish, (1) unauthorized medical information to insurance companies from any hospital or even, (2) a doctor's private office original files. This was done by deceptive impersonation of medical personnel and other resourceful and criminal methods.

Insurance companies evidently wanted complete access to such sensitive records to plan their reserves, and also to use sensitive information as bargaining leverage. For example, in one contested back injury claim the Factual Service Bureau in their procedures discovered a history of venereal disease in the hospital chart. The patient settled his claim at a lower figure rather than have this information disclosed in court. The new Illinois confidentiality law and the APA model law provide penalties for such fraudulent practice.

Now I come to the third major area of problems. I consider this the most important element in the testimony I am presenting. That has to do with the increasing insistence by various legislative bodies that law enforcement agencies have access to physicians' and psychiatrists' records.

Access to medical and psychiatric records by law enforcement agencies has increased dramatically in the past 2 years. These unprecedented threats put into perspective how essential medical privacy and confidentiality are to our democratic process and emphasize how important it is to protect confidentiality and privilege in the areas of insurance and litigation as discussed above. If the doctor-patient relationship is eroded in one area, it soon follows that other areas also will soon be affected. Privacy as a constitutional right must be protected on all fronts.

There has been an increasing trend to use physicians, and particularly psychiatrists, as agents of social control. Laws have been enacted mandating the use of psychiatric records in the assessment of driver's license applicants, drug abusers, gun permit applicants, and child abusers. We are faced with two social rights. It would be convenient to use confidential information for police functions, but to do so vitiates the potential usefulness to society of psychiatric treatment.

The most convincing case for breach of psychiatric confidentiality can be made for the reporting of child abuse, but experience is proving that reporting of child abusers has, because of limited social resources, not been effective. Society will have to determine whether to continue its insistence on such reporting.

The direction of Congress, based upon the action taken with respect to the Domestic Violence Prevention and Services Act, S. 2759, in the 95th Congress, would appear to be toward the need for treatment stimulated by protection of medical record confidentiality as done in Federal alcohol and drug abuse treatment programs as the appropriate priority. I agree.

The treatment of alcohol drug abusers provides another instance in which the need for effective therapy collides with the need for social control. Federal rules and regulations for alcohol and drug abuse programs—Public Law 92-255 and Public Law 93-282—wisely protect the identities of and clinical material of drug abuse clinic patients. Otherwise the patients realistically would not attend the clinics and society would lose even its slim chance to rehabilitate these unfortunate patients.

Despite regulations to the contrary, local police and State officials have demanded access to such clinic records. One New York psychiatrist went to jail to prevent access to his clinic's records. The police wanted pictures of his patients.

In another New York case a crisis intervention center's funds were suddenly withdrawn when the State auditor was refused access to identifiable records without patient consent.

Dr. Nyswander, who initiated the methadone treatment programs, emphasizes in one of her articles the damage done to rehabilitation programs by "politically inspired—police—control."

Another example, which illustrates the increasing trend in this direction, of using the patient-psychiatrist relationship as a mechanism of social control involves the well-known California 1976 *Tarasoff* decision, imposing on psychiatrists a "duty to warn" presumed intended victims of their patients' threatened aggression. This has resulted in many counterproductive complications to the ability of psychiatrists to help their patients.

Some patients who consider themselves marginally dangerous avoid initiating treatment that could help them, lest they be betrayed by their psychiatrist. Some patients have terminated treatment prematurely, leaving themselves and others unnecessarily vulnerable.

The *Tarasoff* decision is another example in which well-intentioned jurisprudence results in the impairment of access of medical treatment by our citizens. An unencumbered psychiatrist-patient relationship is potentially the most effective method to defuse a disequibrated patient.

Now we come to two instances which I consider major examples of what I have in mind. A major erosion of our democratic process resulted from the well-known 1978 U.S. Supreme Court decision in the *Zurcher v. Stanford Daily News* case. The Court upheld the validity of a warrant being issued to search a newspaper's offices for evidence on a crime involving a third party. The impairment of the first amendment right to freedom of the press is readily apparent and corrective legislation is in process over the country, locally and federally. Unfortunately, less readily apparent is the vulnerability of other premises, such as the offices of physicians, lawyers, legislators, or even private homes, to such warrants.

At the hearings before Senator Birch Bayh's Subcommittee on the Constitution in September 1978 it became apparent that if the *Zurcher* decision had been available at the time, President Nixon's "plumbers" could simply have obtained a warrant to search Dr. Fielding's office for Ellsberg's records rather than having to burglarize the premises.

The horror of *Zurcher* to the democratic process is further illustrated by another Palo Alto, Calif., case in which the same sheriff was issued a warrant to search the office and home of a Stanford psychiatrist for evidence of a crime that may have been committed by a patient of hers. No evidence was found. The chilling effect on psychiatrists and patients of such searches is obvious. Even more disconcerting, however, is the fact that the psychiatrist's husband is a famous scientist. His records, too, were rendered accessible by the warrant. I think we can contemplate the scenario about the possibilities for espionage and threats to the national security if such warrants are that readily available.

The drama of *Zurcher* is further compounded by the passage in 1978 of a law, No. 105, in Hawaii authorizing search warrants for "probable cause" defined as "public interest." Thus, should an official swear that a given "provider" treats medicare or medicaid patients and that it is in the public interest to inspect the records involved, a warrant can be issued.

The office of a Hawaiian psychologist has already been searched and not only were the records of his medicare and medicaid patients confiscated, but also those of his private patients. Due process has been unconscionably eroded.

The extrapolation of this trend could result in a situation extant in Uruguay in which a psychiatrist is imprisoned for collusion should he not report the political activities revealed to him by a patient. The abuses of psychiatry in Russia also come to mind.

It is from the background of events illustrated above that the American Psychiatric Association on behalf of its millions of actual and potential citizen-patients objects strongly to the provisos regarding unreasonable access to medical records by law enforcement agencies incorporated into several medical record confidentiality acts being introduced in the 96th Congress. We see these provisos as further examples of a general trend that will eventuate in citizens being unable to avail themselves of psychiatric help and, moreover, a trend that will result in major erosions to our whole democratic system of government.

We recognize the intent of such confidentiality legislation to protect our citizens, but respectfully point out the profound haz-

ards to patients and to democracy provided by allowing access to medical records by law enforcement agencies without due process. Similarly, we object to the elimination of due process by provisos that mandate compliance to a subpena.

We recommend that the cited attached APA model law on confidentiality of health and social service records be studied for its extensive protection of privacy and confidentiality. The feasibility of such legislation is illustrated by the fact that a similar statute has already been enacted in Illinois, effective January 1979, and has been introduced in New York.

I ask that all the cited attachments be made part of the hearing record and inserted at the conclusion of my testimony.

Mr. DRINAN. Without objection, so ordered.

[The material follows:]

OFFICIAL ACTIONS

Model Law on Confidentiality of Health and Social Service Records

This document was approved by the Board of Trustees at its September 1977 meeting and by the Assembly Executive Committee at its February 1978 meeting. It was prepared by the Task Force on Confidentiality of Children's and Adolescents' Clinical Records¹ and the Committee on Confidentiality.²

1. Scope:

All confidential information is subject to the provisions of this Act. Except as hereinafter provided, or otherwise specifically required by federal, state or local law, no person shall, without the authorization of the patient/client or his/her authorized representative:

- (a) Disclose or transmit any confidential information together with a patient/client identifier to any person, or
- (b) Disclose or transmit a patient/client identifier to any person, or
- (c) Disclose or transmit confidential information if the person disclosing or transmitting it has reason to believe that the recipient may have a patient/client identifier for such information.

2. Definitions As Used in This Act:

- (a) "Confidential information" means:
 - (i) The fact that a person is or has been a patient/client;
 - (ii) Information transmitted in confidence between the patient/client and service provider in the course of service provision;
 - (iii) Information relating to diagnosis, facts necessary to the provision of services, or treatment, transmitted in confidence between members of the patient/client's family and the service provider;
 - (iv) Information relating to diagnosis, facts necessary to the provision of service, or treatment, transmitted between any of the persons specified in (a)

- (ii) and (iii) above, and persons who participate in the accomplishment of the objectives of diagnosis, fact-finding, or service under the supervision of, or in cooperation with, the service provider;
- (v) Any diagnosis or opinions formed by the service provider regarding the patient/client's physical, mental or emotional condition;
- (vi) Any advice, instructions or prescriptions issued by the service provider in the course of diagnosis, treatment, or provision of other service;
- (vii) Any summary, resumé or characterization of the substance, or any part of the information described in sub-sections (f), (i) through (v) of this section 2; and
- (viii) Any record, recording, or notation of information described in subsection (f), (i) through (vi) of this section 2, in whatever form and by whatever means recorded or noted.
- (ix) Personal information governed by the School Student Records Act is hereby excluded from the application of this statute.
- (b) "Patient/client" means a person who consults, is examined, interviewed, treated, or is otherwise served to some extent by a service provider, or a clinical researcher, as hereinafter defined, with regard to a medical, mental, or emotional condition or social deprivation or dysfunction.
- (c) "Patient/client identifier" means:
 - (i) The patient/client's name or other descriptive data from which a person well acquainted with the client might, with reasonable certainty, recognize such patient/client as the described person, or
 - (ii) A code, number, or other means to be used to match the patient/client with certain confidential information regarding him/her.
- (d) "Authorized representative" means:
 - (i) A person empowered by the patient/client to assert or to waive the confidentiality, or to disclose or consent to the disclosure of confidential information, as established by this Act. Such person shall not, except by explicit authorization, be empowered to waive confidentiality or to disclose or consent to the disclosure of, confidential information;
 - (ii) If the patient/client is incompetent to assert or waive his rights hereunder, or is in an apparently life threatening or emergency situation, a guardian or conservator, except that pending appointment of such guardian or conservator, the nearest avail-

¹The Task Force on Confidentiality of Children's and Adolescents' Clinical Records (1976-1977) included Frank Rafferty, M.D., chairperson, John Looney, M.D., Herbert Sacks, M.D., and Lenore Petty, M.D., Falk Fellow. Of Counsel: Sandra Nye, J.D., M.S.W.

²The Committee on Confidentiality (1976-1977) included Jerome Beigler, M.D., chairperson, Ben Bursten, M.D., Maurice Grossman, M.D., Alan McLean, M.D., Don Mosher, M.D., Herbert Sacks, M.D., Hugo Van Dooren, M.D., and Robert Friedman, M.D., Falk Fellow. Of Counsel: Sandra Nye, J.D., M.S.W.

- able relative of such patient/client may maintain or waive the confidentiality;
- (iii) If the patient/client is deceased, his personal representative or next of kin or
 - (iv) If the patient/client is less than twelve (12) years of age, his parent or other custodian or guardian.
- (c) "Diagnosis, fact-finding, or provision of service" includes observations made for purposes of same and all efforts to prevent, ameliorate, or otherwise overcome the effects of medical, mental or emotional disorders or social deprivation or dysfunction.
- (f) "In confidence" means, private disclosures made or intended to be made, so far as the discloser is aware, to no other persons except
- (i) The intended recipient;
 - (ii) Those who are present to further the interest of the patient/client in consultation, examination or interview, diagnosis, treatment, or other service provided;
 - (iii) Those to whom disclosure is reasonably necessary for the transmission of the information or the accomplishment of diagnosis or treatment, including members of a therapy group of which the patient/client is a participant, and members of the client's family; supervisors or other persons participating in consultation, examination or interview, diagnosis, or treatment, or other service provided under the direction of the provider; third-party payers; and
 - (iv) Persons reasonably believed to be engaged in good faith in training programs relevant to the activities of the service provided.
- (g) "Person" means any natural person, corporation, association, partnership, and any state, local or federal government, or any agency or other part thereof, including a court.
- (h) "Service provider" means any person authorized by statute to provide medical, psychological, psychotherapeutic, psychoanalytic, child welfare and/or other social services; any person reasonably necessary for evaluation, diagnosis, consultation, treatment, or care under the supervision of the provider; and, any person reasonably believed by the client to be so authorized or engaged.

3. Authorized Disclosures:

- (a) Consent may be given by a patient/client who is twelve (12) years of age or over or by his authorized representative, for the transmission or disclosure of confidential information. Such consent shall be effective only if it is in writing and signed, and also specifies the nature and content of the information to be disclosed, to what person such information may be transmitted or disclosed, and to what use the transmitted or disclosed information may be put. Such specifications shall constitute the limits of the authorization. Every person requesting such authorization shall inform the patient/client or authorized representative that refusal to give such consent will in no way jeopardize his right to obtain present or future service, except where and to the extent disclosure is necessary for service to said patient/client, or for the substantiation of a claim for payment from a person other than the patient/client. The patient/client, or his authorized representative, may withdraw any such consent at any time in writing transmitted to and received by the person authorized

to receive such confidential information. Upon receipt of such withdrawal, the person previously authorized to receive said information shall exercise reasonable care in promptly notifying all persons who had previously transmitted information on the basis of said consent, or who might reasonably be expected to do so in the future, that the prior consent has been withdrawn. If consent had been obtained by a person other than the person thereby authorized to receive said information, the person who obtained said consent shall, upon request, promptly, and in the exercise of reasonable care, assist the patient/client in ascertaining the correct name and address to which the withdrawal should be sent. Withdrawal of such consent shall have no effect upon disclosures made prior thereto.

- (b) If the patient/client is under twelve (12) years of age or incompetent, consent may be given for the transmission or disclosure of confidential information by the patient/client's authorized representative.

4. Disclosures Without Authorization:

Consent from the patient/client shall not be required for the disclosure or transmission of confidential information in the following situations, as specifically limited:

- (a) *Within the service-providing facility:* Confidential information may be disclosed to other individuals employed by the service provider, and to officially designated auditors and surveyors for accreditation, when and to the extent to which the performance of their duties in employment, audit or accreditation requires that they have access to such information. For purposes of this subsection (a), (i) persons engaged in good faith in training programs at a service providing facility and their clinical supervisors are to be considered as being employed by the service provider and may have access to such records and information to the extent reasonably required in their training and duties, but, (ii) individuals employed by the service provider or audit or who are involved in financial audit, preparation of bills or who are otherwise engaged in the collection of charges for services to a patient/client shall not, by virtue thereof alone, have access to confidential records and information, except with respect to names, addresses, and other information essential to the preparation and submission of bills and claims for payment of charges for services to a patient/client.
- (b) *Clinical supervisors or trainers not employed by the service-providing facility:* Confidential information may be disclosed to supervising or training clinicians by service providers who are in training or supervision under a clinician or bona fide training program, whether or not such supervising clinicians are employed by or affiliated with the service-providing facility. For purposes of this subsection (b), the clinical supervisor or trainer receiving such confidential information shall bear the same position and responsibility with regard to the protection thereof as the service provider.
- (c) *Protection from serious injury or disease; The Abused and Neglected Child Reporting Act:* Confidential information may be disclosed, (i) in accordance with the provisions of the Abused and Neglected Child Reporting Act; and (ii), when the statute creating a legislative commission delegates authority to study the needs of minors or incompetents, and to promote services for

the protection of the rights and interest of minors or incompetent persons who are in need of, or provided with medical, social and mental health services; subject, however, to guidelines established by the director of the agency providing the service with respect to the validity of the request for material and to the proper precaution as to its confidentiality and use; (iii) when and to the extent a treating or diagnosing service provider, in his sole discretion, determines that such disclosure is necessary to initiate or continue civil commitment proceedings under the laws of this state or to otherwise protect the patient/client or other person against a clear, imminent risk of serious physical or mental injury or disease or death being inflicted upon the patient/client, or by the patient/client on himself or another; and (iv) when and to the extent such is in the sole discretion of the treating or diagnosing clinician, necessary to the provision of emergency medical care to a patient/client who is unable to assert or waive his rights hereunder and there is no relative or other third party available to give consent. Any person, institution, or agency, under this Act, participating in good faith in the making of a report under the Abused and Neglected Child Reporting Act, or in the disclosure of confidential information otherwise in accordance with this provision, shall have immunity from any liability, civil, criminal or otherwise, that might result by reason of such action.

- (d) **Billing and claims:** Information supplied by a service provider to persons involved in the billing for, or collection of, charges for services, shall be limited to names, addresses, dates on which services were performed, and the amount of charges for such services, and shall not otherwise indicate the nature of the conditions for which services were provided. In the event of a claim in any civil action for payment for services, no other confidential information except names, addresses, the dates on which services were rendered, and the amount of charges for such services shall be disclosed in pleadings and motions, except to the extent necessary (i) to respond to a motion of the client for greater specificity, or (ii) to dispute a defense or counterclaim.

- (e) **Patient/client-litigant exception:** Except as provided in paragraph (ii) of this subsection (e)

- (i) Confidential information may be disclosed in a civil or administrative proceeding in which the client introduces his physical, mental or emotional condition or any aspect of his diagnosis or treatment for such a condition as an element of his claim or defense if and only to the extent the court in which the proceedings have been brought, or, in the case of an administrative proceeding, the court to which an appeal or other action for review of an administrative determination may be taken, finds, after *in camera* examination of testimony or other evidence, that it is relevant, probative, not unduly prejudicial or inflammatory, and otherwise clearly admissible; that other satisfactory evidence, such as the results of a present examination of the patient/client by an examining clinician other than the service provider, or stipulations of fact between the parties, are demonstrably unsatisfactory as evidence of the facts sought to be established by such evidence; and that disclosure is more important to the interests of sub-

stantial justice than protection from injury to the provider-patient/client relationship or to the patient/client or others whom disclosure is likely to harm. No confidential communication between a service provider and a patient/client shall be deemed relevant for purposes of this sub-section, except the fact of treatment, the cost of treatment and the ultimate diagnosis unless the party seeking disclosure of the communication clearly establishes in the trial court a compelling need for its production.

- (ii) This subsection (e) shall not apply to preclude the assertion of the confidentiality privilege as to confidential information disclosed in the course of any treatment of an abnormal mental or emotional condition

- (a) In any action brought or defended under the Divorce Act, or

- (b) In any action for damages for pain and suffering that does not include a claim for the treatment of such abnormal mental or emotional condition.

- (iii) Confidential information or records may be disclosed in a civil proceeding after the patient/client's death when the patient/client's physical or mental condition has been introduced as an element of a claim or defense by any party claiming or defending through or as a beneficiary of the patient/client, provided the court finds, after *in camera* examination of the evidence, that it is relevant, probative, and otherwise clearly admissible; that other satisfactory evidence, including stipulations of fact between the parties, is not available regarding the fact sought to be established by such evidence; and that disclosure is more important to the interests of substantial justice than protection from any injury which disclosure is likely to cause.

- (iv) In the event of a claim made or an action filed by a patient/client, or, following the patient/client's death, by any party claiming as a beneficiary of the patient/client, for injury caused in the course of diagnosis or treatment of said patient/client, the service provider and other persons whose actions are alleged to have been the cause of injury may disclose pertinent confidential information to an attorney or attorneys engaged to render advice about and to provide representation in connection with such matter and to persons working under the supervision of such attorney or attorneys, and may testify as to the said information in any judicial or discovery proceeding for the purpose of preparing and presenting a defense against such claim or action.

- (f) **Court-ordered examination:** Communications made to or diagnoses and opinions made by a service provider in the course of examination ordered by a court for good cause shown may, if otherwise relevant and admissible, be disclosed in a judicial or administrative proceeding in which the patient/client is a party or in appropriate pretrial proceedings, provided such court has found that the patient/client has been as adequately and as effectively as possible informed before submitting to such examination that such communications, diagnoses and opinions would not be considered confidential or privileged. Such communications,

diagnoses and opinions shall be admissible only on issues germane to the said proceedings and involving the patient/client's physical or mental condition.

5. Waiver:

- (a) Particular items of confidential information may be disclosed in judicial proceedings if the court in which the proceedings have been brought finds that the information is relevant and otherwise admissible and that the patient/client or his authorized representative has, without coercion, knowingly waived confidentiality by disclosing, or consenting to disclosure of, the substance of such particular information. In the case of an administrative proceeding, prior to disclosure of confidential information, any dispute as to the issue of waiver of confidentiality shall be referred for determination to the court to which an appeal from the administrative ruling may be taken.
- (b) Disclosures that are privileged, disclosures made in the course of obtaining payment for treatment and related services, and disclosures made in the interest of accomplishing a purpose for which the psychotherapist was consulted are not waivers of confidentiality.
- (c) For purposes of this section 5, failure by the patient/client or his authorized representative to assert the confidentiality of information in any proceeding in which he has the legal standing and opportunity to do so shall be deemed a consent.

6. Rulings on Claims of Confidentiality:

- (a) In a ruling on an assertion of confidentiality to prevent disclosure in judicial or administrative proceedings, the court may not require disclosure of information asserted to be confidential under the Act in order to rule on such assertion.
- (b) When neither the patient/client nor his authorized representative are parties to an administrative or judicial proceeding or they otherwise lack the opportunity to assert confidentiality, (i) any person asked in administrative or judicial proceedings to disclose confidential information may assert its confidentiality; and, (ii) the presiding officer on his own motion or the motion of any party shall exclude such information. Such presiding officer may not exclude information under this section 6 if, (i) he is otherwise instructed by the client or his authorized representative to permit disclosure; or, (ii) the proponent of the evidence establishes that there is no person authorized to assert confidentiality in existence.
- (c) Whenever confidentiality is asserted under this Act in a judicial or administrative proceeding, the party opposing such assertion shall have both the burden of going forward with evidence and the burden of proof with regard to issues of whether confidentiality has been waived and whether any relevant transmissions of information were not made in confidence.
- (d) No person shall be held in contempt for failure to disclose confidential information unless he has failed to comply with a court order, a legislative subpoena or an order of an administrative hearing that he disclose such information.

7. Prescriptions:

Nothing in this Act shall be construed as limiting or interfering with state and federal regulation and monitoring of the

handling and dispensing of prescription drugs; otherwise, however, prescriptions for drugs shall be considered confidential information and subject to the provision of this Act.

8. Research:

Persons engaged in research may have access to confidential information that identifies the patient/client where needed for such research, provided no records thereof shall be removed from the service-providing facility that prepared them. Data that do not identify patient/clients or coded data may be removed from a service-providing facility provided the key to such code shall remain on the premises of the facility and no copies thereof are removed. Where the person engaged in research is to have access to confidential information, the research plan first shall be submitted to, and approved by, an appropriate Research Review Committee and by the director of the service-providing facility or his designee. The service-providing facility, together with the person doing the research, shall be responsible for the preservation of the anonymity of the patient/clients and shall not disseminate data that identify a patient/client except as provided by this Act.

9. Mandatory Cautions:

- (a) All nonoral disclosures of confidential information shall bear the following statement: "The protection of the confidentiality of information contained herein is required under (chapter) of laws of the State of () which provides for damages and penalties for violations. This material shall not be transmitted to anyone without consent or other authorization as provided in the aforementioned statute." A copy of the pertinent consent form specifying to whom and for what specific use such communication or record is disclosed or transmitted, or a statement setting forth any other statutory authorization for disclosure or transmittal and limitations imposed thereon, shall accompany all such nonoral disclosures. In cases of oral disclosure, the person disclosing confidential information shall inform the recipient that such information is confidential under the laws of this state.
- (b) Service providers shall ensure that all persons in their employ or under their supervision are aware of their responsibilities to maintain the confidentiality of information protected by this Act and of the existence of penalties and civil liabilities for violation of this Act.

10. Civil Remedies and Criminal Penalties:

- (a) Any person aggrieved by a violation of this Act may petition the court of common pleas for the county in which he or the alleged violator resides or in which such violation occurred, for appropriate relief, including temporary and permanent injunctions, and such petition shall be first priority with respect to assignment for trial. Such aggrieved person may also prove a cause of action for general or special damages, or both, and, in cases of willful or grossly negligent violations, punitive damages.
- (b) A willful or grossly negligent violation of this Act shall be punishable as a Class C misdemeanor. For purposes of this section, in cases of willful disclosure of confidential information, each such disclosure of information pertaining to any one person shall constitute a separate violation.

11. *Employee Discipline:*

- (a) Any state, county or local government employee and any employee of a service-providing facility operated under contract to a state, county or local government or department or agency thereof, who repeatedly, willfully or through gross negligence violates this Act, shall be dismissed from employment, or, in the case of mitigating circumstances deemed adequate by the employer, appropriately disciplined and transferred to a position, if available and otherwise suitable, outside a service-providing facility and involving no access to confidential information.
- (b) Negligent, nonrepetitive violations of this Act shall render such employees subject to appropriate disciplinary action.
- (c) In the course of any disciplinary or dismissal actions against such employees, confidential information shall not be used except to the extent necessary to comply with principles of fair notice and hearing, and patient/client identifiers shall be removed from any such information prior to its use in such proceedings.
- (d) All contracts between private persons and any state, county or local government or department or agency thereof involving access by such private persons or their employees, representatives, agents or subcontractors shall include a provision setting forth requirements of this section. Failure to include this clause in any such contract shall not limit the operation of this section.

12. *Patient/Client Access to Information:*

- (a) Except as provided in (c) and (d) of this section 12, upon request of a patient/client, a service provider shall, within thirty days following the request, allow the patient/client access to his service record.
- (b) The service provider shall establish procedures that: 1) allow a person to purchase copies of his record at a reasonable cost, not exceeding the actual cost of duplication to the service provider; 2) allow a person to contest the accuracy, completeness or relevancy of the record content; 3) allow information contained therein to be corrected on request of the person when the service provider concurs in the proposed correction; 4) allow a person who believes that the service provider maintains inaccurate or incomplete information concerning him to add a statement to the record setting forth what he believes to be an accurate or complete version of those personal data. Such a statement shall become a permanent part of the service provider's personal data system, and shall be disclosed to any individual, agency or organization to which the disputed personal data are disclosed.
- (c) If a service provider determines that disclosure to a person of medical, psychiatric or psychological data concerning him would be detrimental to that person, or that nondisclosure to a person of personal data concerning him is otherwise required by law, the service provider may refuse to disclose those personal data, and shall refuse disclosure where required by law. In either case, the service provider shall advise that person of his right to appoint another clinician of his own choice as "clinical mediator" to have access to the record. The "clinical mediator" may, upon review of the record, disclose the record to the person, offer to interpret the contents of the record to the per-

son, or may refuse to disclose. If the "clinical mediator" determines against disclosure and the person is unwilling to accept an interpretation of his record, the service provider shall advise the person of his right to seek judicial relief.

- (d) If disclosure of personal data is refused by a service provider under this section 12, the person aggrieved thereby may, within 30 days of such refusal, petition the court of common pleas for the county or judicial district in which he resides or in which the service provider resides or practices, for an order requiring the service provider to disclose the personal data. The court, after hearing and an *in camera* review of the personal data in question, shall issue the order requested unless it determines that such disclosure would be detrimental to the person or is otherwise prohibited by law, or may alternatively authorize disclosure to a designated clinician or attorney.
- (e) If the person is under 12 years of age, his parent or other custodian shall have the rights set forth in this section 12 on behalf of that person. Further, if the person, in consequence of physical or mental incapacity, shall have been placed under guardianship, his guardian shall have the same rights set forth in this section 12 on behalf of that person.

13. *Records and Information Pertaining to Minors:*

- (a) All confidential information pertaining to the provision of health and social services to a minor shall be deemed confidential, and no disclosure of such information shall be made to the child's parent or any other person, except:
 - (i) If a minor who is twelve (12) years of age or older consents in writing;
 - (ii) As provided by sections 4 and 12 (c) hereof;
 - (iii) If the service provider obtains information that he or she believes requires action to prevent serious harm to the minor or another person, he or she may disclose that information to the child's parent, guardian or legal custodian, or as appropriate under the provisions of the Abused and Neglected Child Reporting Act;
 - (iv) All records shall be available to the child's counsel of record and professional and paraprofessional persons associated with the child's counsel and to staff members of the Juvenile Court.

14. *Personal Notes: Special Limitations on Disclosure:*

- (a) A service provider is not required to but may, to the extent he or she determines it necessary and appropriate, keep personal notes regarding a patient/client wherein he or she may record:
 - (i) Sensitive information disclosed to him or her in confidence by other persons on condition that such information would never be disclosed to the patient/client or other persons;
 - (ii) Sensitive information disclosed to him or her by the patient/client that would be injurious to the patient/client's relationships to other persons; and
 - (iii) The service provider's speculations, impressions, hunches and reminders.
- (b) Such personal notes are the work product and personal property of the service provider and shall not be subject to discovery in any judicial, administrative or legislative proceeding or any proceeding preliminary thereto.

15. *Group Health and Life Insurance:*

No person shall demand or request that information as to medical and mental health history, condition and treatment on group health and group life insurance applications, questionnaires and claim forms or any copy thereof or information therefrom, be submitted to an insurance company regarding the insurance coverage of a resident of this state, (a) to or through any member or representative of the group, or (b) to or through the employer or any representative or agent of the employer of the persons covered by such policy, but only directly from the insured or covered persons or their designees and providers of covered health care services or their designees. Insurance companies with group policies covering persons residing in this state and the representatives and agents of such companies, in accordance with rules and regulations to be promulgated by the Director of Insurance, shall, within 120 days from the effective date of this Act (a) take measures to advise group members, employers of group members and representatives and agents of such employers involved in the administration of such policies of the requirements of this section; (b) cause notices regarding this section to be printed prominently on all newly issued or renewal policies, on printed materials intended to be provided to group members and their employers regarding such policies and on all applications, questionnaires, claims and similar forms to be submitted by or on behalf of covered persons and by persons providing covered health care services. For purposes of this section, covered health care services shall include diagnostic and evaluative services. This section shall not apply to applications for life insurance benefit payments.

16. *Health and Life Insurance: Prohibition on Requirement of Consent to Disclosure by Insurance Company to Others:*

No insurance company or any employee, representative or agent thereof shall require of any person residing in this state as a condition of the issuance, continuation, renewal or reinstatement of life, health, accident, medical, hospitalization or similar insurance policy or as a condition of paying any benefits thereunder that an applicant, insured or covered person, or any person acting in his behalf, authorize or agree to authorize such insurance company to disclose or re-disclose confidential information with patient/client identifiers to persons other than itself. Advice that no such requirement may lawfully be imposed must be given in conjunction with any request for such authorization.

17. *State, County and Local Information Systems:*

- (a) *Official inspections:* Nothing in this Act shall be construed as prohibiting any state, county or local government official from performing any audits, investigations or inspections of health or social service facilities in the state as required or authorized by law, provided that the performance of such duties shall not entail removal from any such facility of any confidential information with client identifiers or any codes or keys to electronically processed information.
- (b) *Statistical reports:* Nothing in this Act shall be construed as prohibiting the issuance of statistical reports and similar anonymous data regarding the operations of health or social service facilities.
- (c) *Electronic data processing:*
 - (i) No electronically processed data of confidential information with patient/client identifiers shall be recorded on equipment outside a mental health fa-

cility except in accordance with this section.

- (ii) Confidential information regarding current patient/clients may be recorded on electronic data-processing equipment outside a mental health facility only if:
 1. Such information is encoded by means that make it impossible for persons other than data-processing personnel within such facility to discern the identity of individual patient/clients;
 2. The encoding means or devices by which a patient/client can be identified are delivered, within 60 days after a client is discharged or otherwise ceases to participate in diagnosis or treatment, by data-processing personnel within such facility to a person or persons under the direct supervision of the facility director, which person or persons are strictly denied access to the electronic data-processing equipment and are responsible for the safekeeping of such encoding means or devices and the denial of access thereto to all persons except as provided in subsection (iii) of this section 17;
 3. The encoding means or devices by which a former patient/client can be identified may be returned to data-processing personnel for purposes of reactivating access to confidential information stored on electronic data-processing equipment when and only when, (1) the patient/client to which such information pertains has reentered diagnosis or treatment at such facility, or (2) a request for confidential information that may be honored under the provisions of this Act has been received; and
 4. No later than 5 years after a patient/client has been discharged or has otherwise ceased to receive services at such facility, or in the case of a minor receiving service that was terminated during his minority, no later than 5 years after attaining his majority, either said encoding means or devices pertaining to such patient/client shall be destroyed, or, (2) all electronically processed data pertaining to such patient/client shall be returned to data personnel at such facility. Those facilities planning long-term epidemiological research may request under the research provisions of this statute special informed consent from the patient/client or authorized representative to maintain the patient/client's records for an extended period of time. Treatment may not be denied for failure to consent. The patient/client may at any time cancel consent without prejudice.

- (iii) Such encoding means or devices may be disclosed (aa) to the extent necessary for auditors regularly employed by the state to inspect electronic data equipment to ensure strict and complete compliance with this Act, provided that such inspections shall not involve the removal of such encoded means and devices, or copies or other reproductions thereof from a mental health facility, (bb) or to the extent required for a fair hearing in connection with the dismissal of an employee charged with violating this Act, and (cc) to the extent necessary for use in a civil or criminal action arising out of violations of this Act.
- (d) *Indigency investigations:* Any agency of state, county or local government charged with responsibility to investigate or audit claims of indigency, hardship or sim-

ilar status whereby individuals may receive health or social services without charge or on the basis of reduced charges, shall maintain the confidentiality of the patient/clients in the conduct of such investigations or audits and, upon the completion thereof, shall forward a report to the facility or agency for which prepared and shall keep no record of such investigation by which any patient/client can be identified.

18. *Disclosures Required in Federally Funded Programs:*

- (a) Confidential information may be disclosed to federal departments and agencies to the extent required under federal law to obtain reimbursement for diagnosis, treatment and other social services under federally funded programs for review and audit that are a requisite for participation in federally funded programs.
- (b) Any organization or agency designated under federal law to perform such reviews or audits of the cases of patient/clients who are residents of this state shall maintain the confidentiality of confidential information, shall not disclose confidential information except to the extent required by federal law, and shall destroy the means by which patient/clients can be identified in such information and records containing such information at the earliest opportunity consistent with the requirements of federal law.
- (c) To ensure that confidential information regarding citizens and residents of this state is afforded maximum protection consistent with the provisions of this Act, the directors of each state code department delivering health or social services shall promulgate regulations

that specify the minimum information required pursuant to subsections (a) and (b) of this section 18 and disclosures in excess thereof shall constitute violations of this Act. In the event a demand for confidential information in excess of that provided for in such regulations is made on any health or social service provider in this state upon pain of disallowance of reimbursement or other benefits, such provider shall immediately refer the matter to the director of the appropriate state code department or his designee, who shall, on behalf of such provider, attempt a resolution of the matter either by negotiation or appropriate court action, or by authorizing said provider to disclose if he determines that disclosure is required by federal law. Disclosures pursuant to the preceding sentence shall not constitute violations of this Act if all reasonable measures to assure confidentiality are taken.

- (d) The director of each state code department delivering health or social services shall prepare written notices describing the requirements under any federally funded programs for the disclosure of confidential information and the purposes for such access; and he shall promulgate regulations establishing procedures whereby each person being provided care or other services for which reimbursement will be sought through a federally funded program involving such disclosure will be given such notice at the outset of the delivery of services. Such notices shall provide advice regarding the individual's option not to receive treatment on a basis whereunder such disclosures are required.

Commentary on Model Law on Confidentiality of Health and Social Service Records

BY SANDRA NYE, J.D., M.S.W.

THIS MODEL ACT addresses and incorporates three allied legal concepts: confidentiality, privacy, and testimonial privilege. These are highly technical and frequently misunderstood. Privilege is an evidentiary concept which provides an exception to the general principle of law that courts have the right to every man's evidence. The concept has relevance only in context of the testimonial arena. A testimonial privilege (or shield law) permits those protected by it to withhold testimony or records, notwithstanding a subpoena (1). The right to privacy protects the individual from unsolicited, unwarranted intrusion in the conduct and affairs of his life—including the right to keep to himself information about himself (2). The right of a patient/client to confidentiality—and the concomitant duty of the care provider to maintain the patient/client's confidentiality—inheres in the contractual nature of the provider-patient/client relationship. Implied in the contract is a covenant not to disclose (3, 4).

Part of the complexity of this Model Act arises by reason of the legal principles on which it is based and which it intends to alter. In overturning existing law, every detail to be changed must be explicated. Any concept not expressly altered will remain the law. Thus, the Model Act must not only create and articulate novel concepts and procedures but must expressly eliminate or alter existing ones. For example, it is clearly established by case interpretation of statutory or common law privileges that the identity of a patient/client, the fact of the professional relationship, and purely clerical data—such as dates of service delivery—are not privileged communications and are, therefore, not protected from compelled disclosure in a legal proceeding (5). Further, the presence of a third person who is not a party to the provider-patient/client relationship (e.g., a family member or group member) "pollutes" any privilege that might have existed between the provider and the patient/client (6). Such technicalities as these have severely curtailed the efficacy of the communications privilege as a protection to psychiatric patients.

The Model Act is intended to serve as a basis for examining and proposing changes in local legislation. Although it represents the product of a thorough study of this subject and the combined thinking and expertise of many learned professionals, there are doubtless aspects that may be improved. The caveat to be kept in mind in working with the Act is that much of its phraseology consists of "terms of art." A knowledgeable lawyer should be consulted in any redrafting effort. In the limited space available for annotation, it is not possible to provide thorough explication and legal authority. We ask that the reader take on faith, for the time being, that what appear to be redundancy, prolixity, or

tortured sentence construction translates in "legalese" as meaningful.

1. *Scope.* This Act defines both a communications privilege and a general law of confidential information. Thus, in addition to protecting confidential information from compelled disclosure in a judicial, legislative, or administrative proceeding, it also establishes a positive statutory duty on health and social service providers to maintain patient/client confidentiality. A salient principle of the Act is that all patient/client information given for the purpose of health care and social service delivery must be protected—irrespective of the nature of service delivered or the discipline or professional status of the care provider. This is a significant departure from most existing law, which makes irrational distinctions in protecting information as to care setting and care provider credentials. The needs of the patient/client for privacy and confidentiality do not differ according to whether the care provider is a social worker, a paraprofessional, or a psychiatrist. It should be public policy to mitigate fear of stigmatization (said to be the greatest barrier to seeking mental health services) so as to encourage individuals to seek necessary health and mental health care and social services.

2. *Definitions.* Explicit and detailed definitions are required to extend protection to categories of persons and data heretofore excluded by common law principles and certain statutes.

3. *Authorized Disclosures.* The nature of consent for disclosure is defined and delimited. This section clears up many existing ambiguities and procedural questions and outlines in detail the rights and duties of persons seeking disclosure, of care providers, and of patient/clients.

The minimum age at which consent may be given is established as 12 years. This is consistent with current child development theory recognizing the privacy and confidentiality needs of adolescents receiving mental health treatment and with existing federal and state legislation authorizing persons of this age to consent to certain types of treatment and other services. It is to be noted that parental notification will be automatic in most cases simply by reason of the parent's initiation of or involvement in the service delivered to the minor, or the minor's consent that disclosure be made to his/her parents. In the few cases in which the minor obtains services by reason of legal capacity to do so and does not authorize disclosure to his/her parents, the service provider who deems it necessary to notify the parents in order to protect the minor from serious injury or health hazard has the option under section 4 (c) to do so without the minor's consent or over his/her objection.

4. *Disclosures Without Authorization.* Although the underlying philosophy of the Act is that an individual has the right to control his/her private and confidential information, there is no question but that certain disclosures of such information are not only necessary but appropriate. In recognizing the "need to know," the following principles are essential:

a. Unauthorized disclosures should be kept to a mini-

Ms. Nye is Assistant Professor, Department of Psychiatry, University of Illinois Abraham Lincoln School of Medicine, and Director of Legal Affairs, Jewish Family and Community Services, 1 South Franklin St., Chicago, Ill. 60606.

mum, consistent with the needs of the patient/client and the exigencies of service delivery.

- b. The primary duty of the service provider is to the patient/client. There is no duty upon a provider to protect third parties, but there may be instances in which the provider deems it in the patient/client's interest to disclose confidential information to protect the patient/client or another from serious harm. This is left to the sole discretion of the service provider, who is immunized against liability for any such disclosure in good faith.

The Patient/Client-Litigant Exception (subsection 4 (e)) is an almost universal exception to existing privilege laws. The adage that "confidentiality is to be a shield, not a sword" decrees that a patient/client waives any privilege he may have as to material relevant to the trial of a lawsuit in which he is a party. This section is based in part on guidelines set forth by Judge Shirley Hufstetler in her brilliant dissenting opinion in *Caesar v. Mountanos* (7). It further excludes from the rubric of "mental condition" an action for pain and suffering per se and incorporates a refinement of Illinois law eliminating the exception in divorce cases (8). Strictures are placed on disclosure after the death of the patient/client because the threat of disclosure after death may serve to inhibit communications, particularly in mental health care delivery. This subsection clears up a problem presently existing in some jurisdictions that holds that the privilege expires with its holder.

Court-ordered examination (subsection 4 (f)). Service providers are frequently called upon to conduct examinations for trial purposes. Although clinical skills are utilized in such examinations, the information conveyed is intended to be disclosed, and communications made in the course of such examinations are not protected by a privilege. The relationship of examiner to the subject of the examination is not that of service provider and patient/client. Disclosure should, however, be limited in accordance with the purpose for which it is made.

5. *Waiver*. At common law, a communication not expressly asserted by its holder is deemed waived. This section clarifies the question of waiver and obviates certain "accidental" or "resulting" waivers.

6. *Ruling on Claims of Confidentiality*. This section protects, to the extent possible, confidential information during a controversy as to its discoverability or admissibility in a judicial or administrative proceeding. The person seeking disclosure has the burden of establishing discoverability or admissibility. The court is empowered to protect confidential information in appropriate cases in which there is no person in existence who is otherwise empowered to do so.

7. *Prescriptions*. The patient/client's need for confidentiality is balanced by the interest of the community in regulating drugs.

8. *Research*. Although confidential information disclosed by a patient/client in the course of receiving health and social services is intended by the patient/client to be utilized for his direct benefit in service provision, the value to the community in accessibility of data for research and development cannot be overlooked. This section provides access to data under strictures that will protect the patient/client.

9. *Mandatory Cautions*. The disseminator of confidential information is charged with the instruction of employees and discloses as to the protection of the information he/she is disclosing.

10. *Remedies*. Civil (equitable and legal) relief is authorized for any person aggrieved by violation of this Act. In some

jurisdictions violations of confidentiality statutes have been discouraged by criminal sanctions as well. Alternatives are provided herein.

11. *Employee Discipline*. This section is intended to enable employers to take appropriate action against employees who willfully or by gross negligence violate the Act. Employers are said to fear that, without such provisions, civil service and union procedures will effectively preclude disciplinary action against erring employees who are employed under civil service regulations or union contracts and whose wrongful acts not only injure patient/clients but also expose the employers to liability.

12. *Patient/Client Access to Information*. As a general principle, it is held that every person should have access to any record of information about him. If information is to be disclosed pursuant to consent, such access is probably mandatory. (Consent is not valid unless informed; one cannot give informed consent to disclose unless he/she has knowledge as to the content of the disclosure.) Further, a patient/client should have an opportunity and right to seek correction or at least enter his/her opinion into a record that contains an error or with which he/she disagrees. Experience with allowing patient/client access to records has been positive. At the same time, some clinicians are concerned that there may be occasional instances in which the patient/client will be harmed by such access or the treatment process compromised. A procedure is established that, although possibly cumbersome, will allow access as a general rule and will offer protection in cases in which the service provider deems access to be against the interest of the patient/client.

13. See annotation to Section 3, supra.

14. *Personal Notes*. This concept has been discussed for a number of years as a device by which clinicians can protect records of certain types of data (9). As the public insistence on patient/client right of access to records has grown, some care providers have been concerned about the effect on the individual who discovers unknown facts about him/herself or others or is exposed to speculations and interpretations of the clinician. Some information—although clinically relevant—may be so "sensitive" as to warrant excluding it from the case record entirely. Notes kept by the care provider for use in research, teaching, or supervision may contain material that is inappropriate for the clinical record. Further, by reason of the nature of mental health treatment, certain record content may be highly prejudicial to the patient/client if disclosure is compelled in a judicial or other proceeding.

The "personal notes" concept borrows from a protection afforded "the work product of the attorney." Certain specific types of material can be recorded in the clinician's "personal notes," which are to be utilized by the clinician for his/her own purposes and may not be disclosed or discovered. Concern has been expressed by some administrators and attorneys that this device will afford lazy, careless, or unscrupulous care providers a means of "hiding their wrongdoings" or, at best, neglecting their recordkeeping. Although it is not possible to preclude wrongdoing on the part of any person who is so inclined, the language of the section is eminently plain and clear as to the limited usage of "personal notes." The value of the device in protecting patients and enhancing service provision is deemed to outweigh any possible misuse potential.

15. *Group Health and Life Insurance*. Although the insurance industry denies the charge, there is a widespread belief that it is the major perpetrator of privacy and confidentiality offenses. In any case, care providers and patient/clients have expressed outrage over insurance company demands for in-

formation. A particular source of concern has been the practice of claims processing through employers. This section establishes parameters for data collection by insurers and requires that information about these parameters be supplied to the insured.

16. *Health and Life Insurance Disclosure of Information.* Of the several insurance company practices objected to by providers and patient/clients, one of the most decried is the exchange and dissemination of data among insurers. The practice is widespread; the insurers insist they have a need and right to protect themselves. The many documented abuses of this practice lead to the conclusion that it must be curbed. The interests of the individual and the community in encouraging health care—and particularly mental health care—are held to outweigh the financial interest of the insurers.

17. *State, County and Local Information Systems.* Electronic data collection and storage is perceived as a threat to individual liberty (10). Despite the best intentioned efforts at safeguarding data banks, they are vulnerable to invasion and misuse. Rules for protecting patient/client privacy and confidentiality are established in the light of the realities of audit and accountability requirements.

18. *Disclosures Required in Federally Funded Programs.* The practical exigencies of federal funding are recognized in

this section, with safeguards established for confidential information being disclosed. Notice to the patient/client relative to disclosures and options is required.

REFERENCES

1. Slovenko R: *Psychiatry and Law*. Boston, Little, Brown and Co, 1973, p 61
2. Perr I: Problems of confidentiality and privileged communications in psychiatry. *Leg Med Annu* 1971, pp 327-341
3. *Hammonds v Aetna Casualty Surety Co*, 243 F Supp 793 at 801 (N D Ohio, 1965)
4. *Doe v Roe*, 345 NYS 2d 560, aff'd 33 NY 2d 902, 352 NYS 2d 626, 307 NE 2d 823; 20 ALR 3d 1109 (1977)
5. 97 CJS Witnesses, 283
6. 81 Am Jur 2d Witnesses
7. *Caesar v Mountanos*, 542 F 2d 1064 (9th Cir 1976)
8. Beigler JS: The 1971 amendment of the Illinois statute on confidentiality: a new development in privilege law. *Am J Psychiatry* 129:311-315, 1972
9. Jackson CBJ Jr: Consideration of the "active working record" versus the "permanent record." *Psychiatric Opinion* 12:29-33, 1975
10. Nycum SH: Computer abuses raise new legal problems. *American Bar Journal* 61:444-448, 1975

EDITORIALS

The APA Model Law on Confidentiality

THE MODEL LAW ON CONFIDENTIALITY, prepared jointly by the APA Task Force on Confidentiality of Children's and Adolescents' Clinical Records and the APA Committee on Confidentiality and published elsewhere in this issue, is designed to serve as a prototype for potential enactment in the individual states. The model is broadly drawn; it applies to all medical, psychiatric, and social service records. Although some provisions may be considered controversial, each jurisdiction can decide for itself which are desirable and/or enactable given the local legislative and professional ambience.

The issues of privacy, confidentiality, and the privilege of communications between physician and patient are in the public eye because of the impact of Watergate, the Ellsberg case, the report of the Privacy Protection Study Commission, the proliferation of linked data banks, and the encroachments on privacy by insurance carriers. Several independent groups have fashioned model laws on confidentiality. We believe the APA Model Law is at present most sophisticated from the point of view of our profession.

A law on confidentiality has a much broader reach than does a law on privilege; the latter applies only to doctor-patient privilege in judicial, administrative, and legislative proceedings. Also, most privilege laws have so many exceptions as to be of limited value. A law on confidentiality, on the other hand, must consider the constitutional right to privacy, professional codes of ethics, confidentiality of therapist-patient communications, and rules and regulations regarding hospital records and other health care and social service information. The responsibilities of computer-bank technicians, researchers, insurance companies, and employers must be articulated to protect the privacy of the individual and yet recognize the valid requirements of society vis-à-vis scientific advance and business technology.

The APA Model Law on Confidentiality is a highly technical document and will require expert legal counsel to "translate" some of its provisions. For example, Section 2 on "Definitions" provides the basis for confidentiality to a degree that becomes apparent only as one studies carefully the remainder of the law. Section 3 provides for informed consent in such a way that blanket consent forms cannot be used by insurance carriers; also, patients may revoke previous consent, and unauthorized redisclosures are prohibited. The insurance industry objects to these provisions on the basis of cost, but the public increasingly demands such protection. Several reviewers of the Model Law have objected to the 12-year age of consent, believing this to be too low; others point out that age 7 is stipulated in federal regulations concerning human experimentation. Again, each jurisdiction can decide the specific age of consent according to a local consensus.

Section 4, "Disclosures Without Authorization," is a particularly subtle section providing confidentiality guidelines in situations of training, audit, accreditation, billing, medical emergency, dangerousness, and litigation. Much case law and practical experience has been encompassed in drawing an optimal line between the needs for confidentiality and the legitimate needs of a complex society for information. Paragraph 4 (c) allows breaches of confidentiality for reporting child abuse and also to protect a patient or an intended victim from a dangerous act at

the therapist's sole discretion. This is much different from the "duty to warn" interpreted to have been mandated by the *Tarasoff* decision.

Paragraph 4 (e), "Patient/Client—Litigant Exception," protects communications between a therapist and patient in litigation. Provision is made for testimony by an examining clinician rather than the therapist unless there are unusual circumstances; similarly, the content of the therapist-patient communications is protected unless a compelling need for disclosure is proven. In contrast to most current laws, the balance is changed toward protecting patient-therapist communication. Provision is also made to allow a clinician to defend himself in case of a malpractice action. Similarly, disclosures from a court-ordered psychiatric examination are limited to the patient's clinical condition, thus precluding using the professional examination for a police function.

Of particular current relevance is Section 7, "Prescriptions," which provides that prescriptions constitute confidential information and are thus subject to the Act, but that state and federal drug regulations and laws must be obeyed.

Provisos for confidentiality in a research context have been resisted by epidemiologists and statisticians. The Model Law draws the line at removing patient-identifiable confidential material from the facility providing service. Most statistical and epidemiological research can be carried out through nonidentifiable data; research access to on-site identifiable data must be pre-reviewed by an appropriate research review committee.

Penalties for unauthorized disclosures (Sections 10 and 11) are intended to underline the responsibility of professional and clerical personnel to recognize their responsibilities to maintain the confidentiality of patient records. There is some controversy over whether punitive as well as civil penalties are in order. The APA committees believe that punitive damages for willful or grossly negligent violations of confidentiality are reasonable, but, again, local jurisdictions can modify these stipulations according to their own judgment. Hospital administrators will view provisions for damages with apprehension, but in our information-hungry society the balance of forces must emphasize the importance of privacy, and all personnel must be educated as to their responsibilities to protect the interests and privacy of the patient. The Denver State's Attorney demonstrated that the Factual Services Bureau fraudulently obtained sensitive medical information from hospital and private office charts by impersonating medical personnel. Punitive penalties would help prevent such criminal activity.

Another innovative and perhaps controversial section (Section 12) deals with access by patients to their clinical records. Current federal and state legislation as well as case law provides for access by consumers to data from which decisions modifying their lives may be made by others, such as credit agencies. However, when a physician determines that disclosure of clinical data would be detrimental to the patient, a hierarchy of procedures is established by which a patient may contest that determination. A "clinical mediator" clinician may be appointed by the patient to review the material; if he agrees with the original clinician that the information should not be disclosed, the persistent patient may go to court for a hearing and, if necessary, an *in camera* review of the data.

Another precaution regarding such disclosures is provided in Section 14, "Personal Notes." The concept of a work record of an attorney provides that a lawyer's personal notes regarding a client's case are not "discoverable" in the interest of establishing a circumstance under which a citizen may be free to disclose his troubles to a lawyer in his democratic self-interest. This concept is extended to the work record of a clinician, so that sensitive third-party information can be protected, as well as his own speculations, impressions, and research data. Thus a chilling factor to his research and clinical interests is avoided. This is a pioneer concept and will have to stand the test of time.

Section 15 provides for confidentiality of insurance records. There have been many instances of breach of privacy by employers and/or clerical personnel. Provision is made for bypassing the employer's personnel office and direct communication with the insurance companies. Section 16 prohibits unauthorized redisclosure by the insurance companies to other agencies such as the Medical Information Bureau. The insurance industry may well resist the enactment of these two

sections and in most states may prevail, as they did this past year in Illinois when a Confidentiality Act containing most of the provisions of the APA Model Law was enacted. It is hoped that implementation of the recommendations of the Privacy Protection Study Commission by Congress will neutralize this aspect of insurance applications and claims.

Sections 17 and 18 formulate guidelines for state, county, local, and federal agencies in performing audits, inspections, and investigations. There have been many instances in which auditors and police agencies have demanded access to sensitive records, thereby destroying the effectiveness of psychiatric and drug-abuse clinics. The principle has been established that funding per se does not entitle complete access to identifiable clinical records. Government agents must become educated to their responsibility to protect the privacy of citizens, including those who receive agency largesse.

Similar problems exist with data processing. Linkages of various data banks allow the profiling of private citizens to a surprising extent through use of Social Security or driver's license numbers. Paragraph 17 (c) has been designed to help counter such unauthorized invasions of privacy. At present most government agencies will resist such attempts at regulation, but, again, it is a matter of persistent education of the consumer, the profession, and the bureau.

In some states the APA Model Law will represent such a radical advance that it will not be enactable at present. As already noted, in Illinois most of the model has been enacted, even though it was necessary to omit the section dealing with insurance matters because of the effectiveness of the insurance industry lobby in order to save the remainder of the bill. Similarly, it was necessary to provide access to the state's attorneys for investigative purposes, but with the proviso that unauthorized redisclosure is prohibited. It is also of interest that similar legislation was recently introduced into Congress as S 3450 under the joint sponsorship of Senators Javits, Muskie, and Ribicoff.

Because of the public's interest in preserving privacy, it has been predicted that in ten years all states will have privacy laws. Psychiatrists, because they are particularly sensitive to confidentiality as a prerequisite to the effectiveness of their work, are among the leaders in effectuating such legislation. The APA Model Law incorporates our expertise. Most lawyers will be opposed to many of its provisions. Just as we require confidentiality for our work, lawyers require complete discovery of information. Our professional interests are antithetical but are subject to education, negotiation, legislation, and litigation. It is in the interest of society, our patients, and our profession that confidentiality laws be enacted in each state. The Model Law can serve as a prototype lending itself to local modifications. The APA Committee is available for consultation.

JEROME S. BEIGLER, M.D.

Dr. Beigler is Chairperson, APA Committee on Confidentiality, and President, Illinois Psychiatric Society, 55 East Monroe St., Suite 3510, Chicago, Ill. 60603.



**MENTAL HEALTH AND DEVELOPMENTAL
DISABILITIES CONFIDENTIALITY ACT**

Effective January 1, 1979

**State of Illinois
Department of Mental Health and
Developmental Disabilities**

MENTAL HEALTH AND DEVELOPMENTAL DISABILITIES CONFIDENTIALITY ACT

AN ACT to protect the confidentiality of records and communications of recipients of mental health or developmental disability services, and to amend and repeal certain Acts and Sections herein named in connection therewith.

Be it enacted by the People of the State of Illinois, represented in the General Assembly:

ARTICLE I

Section 1. This Act shall be known and may be cited as the "Mental Health and Developmental Disabilities Confidentiality Act".

Section 2. The terms used in this Act, unless the context requires otherwise, have the meanings ascribed to them in this Section.

(1) "Confidential communication" or "communication" means any communication made by a recipient or other person to a therapist or to or in the presence of other persons during or in connection with providing mental health or developmental disability services to a recipient. Communication includes information which indicates that a person is a recipient.

(2) "Guardian" means a legally appointed guardian or conservator of the person.

(3) "Mental health or developmental disabilities services" or "services" includes but is not limited to examination, diagnosis, evaluation, treatment, training, pharmaceuticals, aftercare, habilitation or rehabilitation.

(4) "Personal notes" means:

(i) information disclosed to the therapist in confidence by other persons on condition that such information would never be disclosed to the recipient or other persons;

(ii) information disclosed to the therapist by the recipient which would be injurious to the recipient's relationships to other persons, and

(iii) the therapist's speculations, impressions, hunches, and reminders.

(5) "Parent" means a parent or, in the absence of a parent or guardian, a person in loco parentis.

(6) "Recipient" means a person who is receiving or has received mental health or developmental disabilities services.

(7) "Record" means any record kept by a therapist or by an agency in the course of providing mental health or developmental disabilities service to a recipient concerning the recipient and the services provided. Record does not include the therapist's personal notes, if such notes are kept in the therapist's sole possession for his own personal use and are not disclosed to any other person, except the therapist's supervisor, consulting therapist or attorney. If at any time such notes are disclosed, they shall be considered part of the recipient's record for purposes of this Act. Record does not include testing material used in the course of providing services if the disclosure of such material would compromise the objectivity or fairness of the testing process.

(8) "Record custodian" means a person responsible for maintaining a recipient's record.

(9) "Therapist" means a psychiatrist, physician, psychologist, social worker, or nurse providing mental health or developmental disabilities services or any other person not prohibited by law from providing such services or from holding himself out as a therapist if the recipient reasonably believes that such person is permitted to do so. Therapist includes any successor of the therapist.

Section 3. (a) All records and communications shall be confidential and shall not be disclosed except as provided in this Act.

(b) A therapist is not required to but may, to the extent he determines it necessary and appropriate, keep personal notes regarding a recipient. Such personal notes are the work product and personal property of the therapist and shall not be subject to discovery in any judicial, administrative or legislative proceeding or any proceeding preliminary thereto.

Section 4. (a) The following persons shall be entitled, upon request, to inspect and copy a recipient's record or any part thereof:

- (1) the parent or guardian of a recipient who is under 12 years of age;
- (2) the recipient if he is 12 years of age or older;
- (3) another person on such recipient's behalf if the recipient so authorizes in writing;
- (4) the parent or guardian of a recipient who is at least 12 but under 18 years, if the recipient is informed and does not object or if the therapist does not find that there are compelling reasons for denying such access. The parent or guardian who is denied access by either the recipient or the therapist may petition a court for access to the record; or
- (5) the guardian of a recipient who is 18 years or older.

(b) Assistance in interpreting the record may be provided without charge and shall be provided if the person inspecting the record is under 18 years of age. However, access may in no way be denied or limited if the person inspecting the record refuses such assistance. A reasonable fee may be charged for duplication of a record.

(c) Any person entitled to access to a record under this Section may

submit a written statement concerning any disputed or new information, which statement shall be entered into the record. Whenever any disputed part of a record is disclosed, any submitted statement relating thereto shall accompany the disclosed part. Additionally, any person entitled to access may request modification of any part of the record which he believes is incorrect or misleading. If such request is refused, the person may seek a court order to compel modification.

(d) Whenever access or modification is requested, the request and any action taken thereon shall be noted in the recipient's record.

Section 5. (a) Except as provided in Sections 6 through 11 of this Act, records and communications may be disclosed only with the written consent of:

(1) the parent or guardian of a recipient who is under 12 years;

(2) both the parent or guardian of a recipient who is at least 12 but under 18 years and the recipient. If only the recipient refuses to consent there shall be no disclosure unless the therapist finds that such disclosure is in the best interests of such recipient. If the parent or guardian refuses to consent, disclosure shall not be made; or

(3) the recipient if he is 18 years or older or his guardian if he has been adjudicated incompetent.

(b) Every consent form shall be in writing and shall specify the following:

(1) the person or agency to whom disclosure is to be made;

(2) the purpose for which disclosure is to be made;

(3) the nature of the information to be disclosed;

(4) the right to inspect and copy the information to be disclosed;

(5) the consequences of a refusal to consent, if any; and

(6) the fixed period of time for which the consent is valid; and

(7) the right to revoke the consent at any time.

The consent form shall be signed by the person entitled to give consent and the signature shall be witnessed by a person who can attest to the identity of the person so entitled. A copy of the consent and a notation as to any action taken thereon shall be entered in the recipient's record.

(c) Only information relevant to the purpose for which disclosure is sought may be disclosed. Blanket consent to the disclosure of unspecified information shall not be valid. Advance consent may be valid only if the nature of the information to be disclosed is specified in detail and the duration of the consent is indicated. Consent may be revoked in writing at any time; any such revocation shall have no effect on disclosures made prior thereto.

(d) No person or agency to whom any information is disclosed under this

Section may redisclose such information unless the person who consented to the disclosure specifically consents to such redisclosure.

(e) Except as otherwise provided in this Act, records and communications shall remain confidential after the death of a recipient and shall not be disclosed unless the recipient's representative, as defined in the Probate Act of 1975, approved August 7, 1975, as now or hereafter amended, and the therapist consent to such disclosure or unless disclosure is authorized by court order after in camera examination and upon good cause shown.

(f) Paragraphs (a) through (e) of this Section shall not apply to and shall not be construed to limit insurance companies writing Life, Accident or Health insurance as defined in Section 4 of the Illinois Insurance Code, as now or hereafter amended, and Non-Profit Health Care Service Plan Corporations, writing Health Care Service contracts, under The Non-profit Health Care Service Plan Act, as now or hereafter amended, in obtaining general consents for the release to them or their designated representatives of any and all confidential communications and records kept by agencies, hospitals, therapists or record custodians, and utilizing such information in connection with the underwriting of applications for coverage for such policies or contracts, or in connection with evaluating claims or liability under such policies or contracts, or coordinating benefits pursuant to policy or contract provisions.

Section 6. Such information from a recipient's record as is necessary to enable him to apply for or receive benefits may be disclosed with consent obtained pursuant to Section 5 of this Act. Disclosure may be made without consent when despite every reasonable effort it is not possible to obtain consent because the person entitled to give consent is not capable of consenting or is not available to do so. The recipient shall be informed of any disclosure made without consent. The information disclosed without consent under this Section may include only the identity of the recipient and therapist and a description of the nature, purpose, quantity, and date of the services provided. Any request for additional information shall state with particularity what further information is needed and the reasons therefor. Refusal to consent to the disclosure of more information than is necessary to apply for or receive direct benefits shall not be grounds for in any way denying, limiting, or cancelling such benefits or refusing to accept an application or renew such benefits. Such information shall not be redisclosed except with the consent of the person entitled to give consent.

Section 7. When a therapist or agency which provides services is being reviewed for purposes of funding, accreditation, audit, licensure, statistical compilation, research, evaluation, or other similar purpose, a recipient's record may be used by the person conducting the review to the extent that this is necessary to accomplish the purpose of the review, provided that personally identifiable data is removed from the record prior to the use. Personally identifiable data may be disclosed only with the consent obtained pursuant to Section 5 of this Act. Funding, accreditation, licensure, and the like may not be withheld or withdrawn for failure to disclose personally identifiable data if consent is not obtained.

Section 8. In the course of an investigation, a regional human rights authority of the Guardianship and Mental Health Advocacy Commission created by the Guardianship and Mental Health Advocacy Act enacted by the 80th General Assembly may inspect and copy any recipient's records in the possession of a therapist or agency which provides services. However, a regional authority may not inspect or copy records containing personally identifiable data which cannot be removed without imposing an unreasonable burden on the therapist or agency which provides services, except as provided herein. The regional authority shall give written notice to the person entitled to give consent for the identifiable recipient of services under Section 4 that it is conducting an investigation and indicating the nature and purpose of the investigation and the need to inspect and copy the recipient's record. If the person notified objects in writing to such inspection and copying, the regional authority may not inspect or copy the record. The therapist or agency which provides services may not object on behalf of a recipient.

Section 9. (a) In the course of providing services, a therapist may disclose a record or communications without consent to:

- (1) the therapist's supervisor, a consulting therapist, members of a staff team participating in the provision of services, a record custodian, or a person acting under the supervision and control of the therapist;
- (2) persons conducting a peer review of the services being provided; and
- (3) an attorney or advocate consulted by a therapist or agency which provides services concerning the therapist's or agency's legal rights or duties in relation to the recipient and the services being provided.

Information may be disclosed under this Section only to the extent that knowledge of the record or communications is essential to the purpose for which disclosure is made and only after the recipient is informed that such disclosure may be made. A person to whom disclosure is made under this Section shall not redisclose any information except as provided in this Act.

Section 10. (a) Except as provided herein, in any civil, criminal, administrative, or legislative proceeding, or in any proceeding preliminary thereto, a recipient, and a therapist on behalf and in the interest of a recipient, has the privilege to refuse to disclose and to prevent the disclosure of the recipient's record or communications.

- (1) Records and communications may be disclosed in a civil or administrative proceeding in which the recipient introduces his mental condition or any aspect of his services received for such condition as an element of his claim or defense, if and only to the extent the court in which the proceedings have been brought, or, in the case of an administrative proceeding, the court to which an appeal or other action for review of an administrative determination may be taken, finds, after in camera examination of testimony or other evidence, that it is relevant, probative, not unduly prejudicial or inflammatory, or otherwise clearly admissible; that other satisfactory evidence is demonstrably unsatisfactory as evidence of the facts sought to be established by such evidence; and that disclosure is more important to the interests of substantial

justice than protection from injury to the therapist-recipient relationship or to the recipient or other whom disclosure is likely to harm. No record or communication between a therapist and a recipient shall be deemed relevant for purposes of this subsection, except the fact of treatment, the cost of services and the ultimate diagnosis unless the party seeking disclosure of the communication clearly establishes in the trial court a compelling need for its production. However, for purposes of this Act, in any action brought or defended under the "Illinois Marriage and Dissolution of Marriage Act", approved September 22, 1977, as now or hereafter amended, or in any action in which pain and suffering is an element of the claim, mental condition shall not be deemed to be introduced merely by making such claim and shall be deemed to be introduced only if the recipient or a witness on his behalf first testifies concerning the record or communication.

(2) Records or communications may be disclosed in a civil proceeding after the recipient's death when the recipient's physical or mental condition has been introduced as an element of a claim or defense by any party claiming or defending through or as a beneficiary of the recipient, provided the court finds, after in camera examination of the evidence, that it is relevant, probative, and otherwise clearly admissible; that other satisfactory evidence is not available regarding the facts sought to be established by such evidence; and that disclosure is more important to the interests of substantial justice than protection from injury which disclosure is likely to cause.

(3) In the event of a claim made or an action filed by a recipient, or, following the recipient's death, by any party claiming as a beneficiary of the recipient for injury caused in the course of providing services to such recipient, the therapist and other persons whose actions are alleged to have been the cause of injury may disclose pertinent records and communications to an attorney or attorneys engaged to render advice about and to provide representation in connection with such matter and to persons working under the supervision of such attorney or attorneys, and may testify as to such records or communication in any administrative, judicial or discovery proceeding for the purpose of preparing and presenting a defense against such claim or action.

(4) Records and communications made to or by a therapist in the course of examination ordered by a court for good cause shown may, if otherwise relevant and admissible, be disclosed in a judicial or administrative proceeding in which the recipient is a party or in appropriate pretrial proceedings, provided such court has found that the recipient has been as adequately and as effectively as possible informed before submitting to such examination that such records and communications would not be considered confidential or privileged. Such records and communications shall be admissible only as to issues involving the recipient's physical or mental condition and only to the extent that these are germane to such proceedings.

(5) Records and communications may be disclosed in a proceeding under the Probate Act of 1975, approved August 7, 1975, as now or hereafter amended, to determine a recipient's competency or need for guardianship, provided that the disclosure is made only with respect to that issue.

(6) Records and communications may be disclosed when such are made during treatment which the recipient is ordered to undergo to render him fit to stand trial on a criminal charge, provided that the disclosure is made only with respect to the issue of fitness to stand trial.

(7) Records and communications of the recipient may be disclosed in any civil or administrative proceeding involving the validity of or benefits under a life, accident, health or disability insurance policy or certificate, or Health Care Service Plan Contract, insuring the recipient, but only if and to the extent that the recipient's mental condition, or treatment or services in connection therewith, is a material element of any claim or defense of any party, provided that information sought or disclosed shall not be redisclosed except in connection with the proceeding in which disclosure is made.

(8) Records or communications may be disclosed when such are relevant to a matter in issue in any action brought under this Act and proceedings preliminary thereto, provided that any information so disclosed shall not be utilized for any other purpose nor be redisclosed except in connection with such action or preliminary proceedings.

(b) Before a disclosure is made under this Section, any party to the proceeding or any other interested person may request an in camera review of the record or communications to be disclosed. The court or agency conducting the proceeding may hold an in camera review on its own motion. When, contrary to the express wish of the recipient, the therapist asserts a privilege on behalf and in the interest of a recipient, the court may require that the therapist, in an in camera hearing, establish that disclosure is not in the best interest of the recipient. The court or agency may prevent disclosure or limit disclosure to the extent that other admissible evidence is sufficient to establish the facts in issue. The court or agency may enter such orders as may be necessary in order to protect the confidentiality, privacy, and safety of the recipient or of other persons. Any order to disclose or to not disclose shall be considered a final order for purposes of appeal and shall be subject to interlocutory appeal.

Section 11. Records and communications may be disclosed, (i) in accordance with the provisions of the Abused and Neglected Child Reporting Act, approved June 26, 1975, as now or hereafter amended; (ii), when, and to the extent, a therapist, in his sole discretion, determines that such disclosure is necessary to initiate or continue civil commitment proceedings under the laws of this State or to otherwise protect the recipient or other person against a clear, imminent risk of serious physical or mental injury or disease or death being inflicted upon the recipient, or by the recipient on himself or another; (iii) when and to the extent such is, in the sole discretion of the therapist, necessary to the provision of emergency medical care to a recipient who is unable to assert or waive his rights hereunder and there is no relative or other third party available to give consent; and (iv) in commitment proceedings under the "Mental Health and Developmental Disabilities Code", enacted by the 80th General Assembly, and proceedings and investigations preliminary thereto, to the State's Attorney for the county of residence of a person for whom involuntary or judicial admission is sought, or in which such person is found, or in which the facility is

located, provided that the information so disclosed shall not be utilized for any other purpose nor be redisclosed except in connection with such proceedings or investigations. Any person, institution, or agency, under this Act, participating in good faith in the making of a report under the Abused and Neglected Child Reporting Act, approved June 26, 1975, as now or hereafter amended, or in the disclosure of records and communications otherwise in accordance with this provision, shall have immunity from any liability, civil, criminal or otherwise, that might result by reason of such action. For the purpose of any proceeding, civil or criminal, arising out of a report or disclosure in accordance with this provision, the good faith of any person, institution, or agency so reporting or disclosing shall be presumed.

Section 12. (a) If the United States Secret Service requests information from the Department of Mental Health and Developmental Disabilities relating to a specific recipient and the Director of the Department determines that disclosure of such information may be necessary to protect the life of a person under the protection of the Secret Service, only the following information may be disclosed: the recipient's name, address, and age and the date of any admission to or discharge from a Department facility.

(b) The Department of Mental Health and Developmental Disabilities and all private hospitals are required, as hereafter described in this subsection, to furnish the Department of Law Enforcement only such information as may be required for the sole purpose of determining whether an individual who may be or may have been a patient is disqualified because of that status from receiving or retaining a Firearm Owner's Identification Card under subsection (e) of Section 8 of "An Act relating to the acquisition, possession and transfer of firearms and firearm ammunition", approved August 3, 1967, as amended. Any such information disclosed under this subsection shall remain privileged and confidential, and shall not be redisclosed nor utilized for any other purpose. The method of requiring the providing of such information shall guarantee that no information is released beyond what is necessary for this purpose. One acceptable method is that of periodically providing lists to the Department of Mental Health and Developmental Disabilities or any private hospital of Firearm Owner's Identification Card applicants on which the Department or hospital shall indicate the identities of those individuals who are to its knowledge disqualified from having a Firearm Owner's Identification Card for reasons described herein. The Department may provide for a centralized source of information for the State on this subject under its jurisdiction.

For purposes of this subsection (b) only, the following terms shall have the meaning prescribed:

(1) "Hospital" means only that type of institution which is providing full-time residential facilities and treatment for in-patients and excludes institutions, such as community clinics, which only provide treatment to out-patients.

(2) "Patient" shall mean only a person who is an in-patient or resident of any hospital, not an out-patient or client seen solely for periodic consultation.

Section 13. Whenever disclosure of a record or communication is made without consent pursuant to this Act or whenever a record is used pursuant to Sections 7 and 8 of this Act, a notation of the information disclosed and the purpose of such disclosure or use shall be noted in the recipient's record together with the date and the name of the person to whom disclosure was made or by whom the record was used.

Section 14. Any agreement purporting to waive any of the provisions of this Act is void.

Section 15. Any person aggrieved by a violation of this Act may sue for damages, an injunction, or other appropriate relief. Reasonable attorney's fees and costs may be awarded to the successful plaintiff in any action under this Act.

Section 16. Any person who knowingly and wilfully violates any provision of this Act is guilty of a Class A misdemeanor.

Section 17. The Director of the Department of Mental Health and Developmental Disabilities shall adopt rules and regulations to implement this Act.

This Act takes effect January 1, 1979.

This Act amends the following:

Chapter 51, Evidence, par. 5.1

Chapter 23, Charities and Public Welfare, "Social Workers Registration Act", par. 5320 (Note: Transferred to Ch. 111, Professions and Occupations).

Chapter 91½, Mental Health, "Psychologists Registration Act", par. 406 (Note: Transferred to Ch. 111, Professions and Occupations).

This Act repeals par. 5.2 of Chapter 51, Evidence.

CONFIDENTIALITY AND THIRD PARTIES

A Report of the APA Task Force on Confidentiality as It Relates to
Third Parties

Maurice Grossman, M.D., Chairperson
Jack D. Barchas, M.D.
Richard G. Johnson, M.D.
Alan L. Krueger, M.D.
Joseph Satten, M.D.

Approved for publication by the Council on
Professions and Associations

Lewis L. Robbins, M.D., Chairperson
Ruth Barnard, M.D.
Robert S. Garber, M.D.
Norman Q. Brill, M.D.
William R. Sorum, M.D.
Martin Booth, M.D. (Observer-Consultant)
Harry H. Brunt, Jr., M.D. (Assembly Liaison)
Donald W. Hammersley, M.D. (Staff Coordinator)

American Psychiatric Association
1700 Eighteenth Street, N.W.
Washington, D.C. 20009

CONTENTS

Introduction: General Principles Governing Confidentiality of Psychiatric Treatment and Disclosures to Third Parties . . .	iv
Definition of Purpose	1
Recommendations Regarding Education Coordination With Other Agencies and the Need for an Ongoing Group	9
Acknowledgements	12
Appendices	
A. General Principles Governing Confidentiality	13
B. Proposed Coding for Mental Disorders	14
C. Position Statement on the Need for Preserving Confidentiality of Medical Records in Any National Health Care System	20
D. Position Statement on The Role of Confidentiality in Volunteer Military Drug Abuse Treatment Programs	21
E. Recommendations of the Task Force on Confidentiality as It Relates to Third Parties to the Council on Professions and Associations, October, 1971	23
F. Principles Governing Confidentiality and Disclosures to Third Parties (September, 1973)	27
G. Testimony (with Addenda) Submitted on Behalf of the American Psychiatric Association and the American Academy of Psychiatry and the Law on the Inclusion of a Strengthened Rule 504 (Psychotherapist-Patient Privilege) in the Federal Code of Evidence, H.R. 5463	36
H. Samples of Reports from Psychiatrists of Injuries to Patients Resulting from Breaches of Confidentiality	53

INTRODUCTION

GENERAL PRINCIPLES GOVERNING CONFIDENTIALITY OF PSYCHIATRIC TREATMENT AND DISCLOSURES TO THIRD PARTIES

The constitutional right to be secure in home and person is the basis of the general right to privacy all citizens are entitled to. In medicine this extends to the right of the patient to be secure in the privacy of his communications with his physician. In psychiatry, where it is the very essence of the profession to deal with the most private corners of the patient's personal life, security from abuses of privacy form a condition without which it would be difficult to practice psychiatry and psychotherapy at all.

Thus there is concensus in the medical world, the legal community and the general philosophy of our system of government that confidentiality of private communication is a right. In particular, psychiatric treatment requires a secure atmosphere of confidentiality in order to protect the patient's right to the pursuit of health and happiness. To create an affirmative and secure atmosphere of confidentiality will encourage individuals who need help to seek it without fear that there will be destructive disclosure to the rest of the community. In fact, the mere disclosure of the fact of psychiatric treatment is sometimes felt to be a hazard to the patient. Further, some diagnostic terms have discriminating social connotations and can cause injury to patients if made known to others.

The patient himself bears some responsibility to protect his own rights. Our position as the patient's physician also makes us responsible for the preservation of confidentiality. This responsibility is even more crucial when the patient's ability to protect his confidentiality is impaired by temporary regression incident to the therapeutic process, by his psychological state of function, or when, under financial duress, the patient permits release of information the consequences of which he only dimly perceives.

The unfettered ability to maintain absolute confidentiality in psychiatry seems desirable. However, problems are created when third parties have legitimate ethical rights to some information about a patient, his treatment process, or even certain specific elements of the treatment itself. Balancing these conflicting interests thus be-

comes the task of the psychiatrist. We must protect the integrity of the psychiatric process and the patient's clear right to privacy. But we are also asked to recognize that some information, usually with the patient's consent, and for advantages important to the patient, may properly be released to third parties. Lastly, in certain rare and special cases, our obligation to society may supersede the patient's rights.

Finding this balance is often not easy. It could be destructive to a patient to refuse to give information about him to a third party having a legitimate right to it. It would be destructive to the patient to reveal too much information. It would be extremely destructive to the treatment process also if the psychiatrist were knowingly to collude in a manipulation of facts. This search for the proper balance is generally best carried out in cooperation and discussion with the patient in the course of which it is the psychiatrist's responsibility to determine whether the patient's consent is truly informed and not based on either misunderstanding or coercion.

Those rare and special circumstances in which a physician's obligation to consider hazards to society may outweigh obligation to preserve the privacy of the patient, are crises in which there is clear, present and extreme danger to life or limb directed by the patient toward others or self. Such crises are often technical treatment problems and should, if possible, be handled within the context of treatment. Possibly outside consultation may be of help and should be carefully considered. Once, however, if in the psychiatrist's judgment this extreme danger from the patient toward self or others can no longer be contained within the treatment, protection of the patient or others may require a breach of confidentiality. In these circumstances confidentiality should be broken only to the extent necessary.

The principle that confidentiality should only be broken to the minimum degree necessary to achieve its desired end applies to all circumstances in which third parties have a legitimate right to information. These will be dealt with in turn.

Among the most common third parties requesting information about the patient or his treatment are family members. Here the psychiatrist must judge whether the disclosure of information will work for or against the patient. Where families, spouses, parents or children are involved it is wise to spell out the standards of confidentiality in the earliest stages of treatment. Even when the decision is to withhold all information, the family should not be entirely ignored but should be helped with whatever support is appropriate, for the emotional state of the family often directly affects the patient and his treatment.

When schools become the requesting third parties the decision to disclose also rests on whether such disclosure works for or against the patient. Often a school will modify its program in a therapeutic way if given appropriate information by the psychiatrist. On the other hand, there is the complication that such information may find its way into permanent school records where it will eventually become out of date and may be available to personnel who do not have the benefit of direct consultation with the psychiatrist. The fate of information once it is released to a third party is a serious problem, and efforts must be made to see that confidential information released to one third party remains confidential with respect to other third parties.

Employers become third parties requesting information in certain occupations where emotional health is felt to be significant in carrying out responsibilities. Generally, psychiatric examination to determine suitability for employment should be carried out independently of treatment and the treating psychiatrist. The judgment in such employment situations should rest on observable job behavior and not on the fact that the employee is in treatment. The long run advantage is to the employer as well as the employee if indicated treatment is sought early, and it is counter-productive for both if the treatment process stigmatizes an employee or makes him vulnerable to dismissal.

The second way in which an employer may request information about an employee's treatment comes from the fact that employers often pay a part or all of the employee's insurance premium. The employer, therefore, needs actuarial information about his employees' use of the insurance program so he may have the data from the insurance carrier that determines premiums to be paid and the cost benefit of his employer insurance program. In such cases information given to employers (or labor unions) should be in the aggregate and should never reveal specific information about an individual employee. Such aggregate data is sufficient for the purposes required and release of any more detailed information would constitute an unwarranted abrogation of confidentiality.

This brings us to the most important third party, the insurance company. Persons enroll in insurance programs to protect their future health and welfare. It therefore follows that the insurance company ought to do nothing which would defeat this aim. On the other hand, the insurance company has the right and some might even argue the responsibility to see that claims are justified and appropriate. It should do so, however, always in a way which will not undermine the patient's health and welfare. Any patient receiving care from any system of paying should have access to all medical services without jeopardizing privacy or confidential relationships with physicians.

Some insurance contracts limit coverage to certain illnesses or certain time periods, therefore insurance companies are entitled to information about patients which is pertinent to these areas. Thus it is necessary in many contracts to demonstrate that an illness did not exist prior to the effective date of the policy. Usually an indication that the patient had an illness which needs treatment is required. To substantiate the type and frequency of treatment given it may be necessary to give some information indicating the general degree of impairment the patient suffers unless treated. This information may be needed too for billing purposes. Finally, the fact that the patient suffers from a psychiatric condition covered by the contract may need to be stated. But in no case should a patient stricken by a condition be penalized because he has added a "burden" to the group. Furthermore, when the cost accounting of a group is made the individual's privacy should not be compromised and all data should be reported in the aggregate. The insurance companies' legitimate right to some information concerning patients is circumscribed. The precise diagnosis and even current "degree of disability" is probably not germane to the policy needs nor helpful to the insurance industry in answering the questions raised, when they follow the general medical model for actuarial purposes. They can usually be replaced by a general category of functional impairment. No information should be given which could in any way be used against the patient. Communications by psychiatrists with an insurance company should be directly with its physician representative, thus subjecting the receiving physician to the same ethical standards of confidentiality the treating physician has. If eligibility to enroll in an insurance program is in question, as it often is in life insurance and some health insurance, the matter should be determined by an examination designed for that purpose, and not by information from the treating psychiatrist.

Any national health insurance program should include strict safeguards of confidentiality built into any data collection or storage system. We must assure that the minimum necessary demographic and health information about the individual be separated from national health statistics. Accessibility to this data must be sharply and carefully limited.

One special sub-category of confidentiality is that of privilege. Here the third party is the court and special legal parameters apply. While it is not necessary here to go into great detail about privilege, we do feel that many of the same principles governing confidentiality also apply to privilege. (For clarification of the distinction between confidentiality and privilege see "Position Statement on Guidelines for Psychiatrists: Problems in Confidentiality", *American Journal of Psychiatry*, 126:10, 187-193, April, 1970.)

When information is requested it is the psychiatrist's responsibility to explore with the patient the risks of breaking or relinquishing the privilege, and he should discuss the nature of the material which might be divulged. When asked to testify the psychiatrist must be one of the agents protecting the patient's best interests. If information is demanded and legal recourse has been exhausted, only that information specifically required should be revealed and no more. And we should as psychiatrists work for the establishment of privileged statutes which will maximally protect a patient's privacy and the confidentiality of their treatment.

From the foregoing some basic principles can be extracted. These are enumerated following.

DEFINITION OF PURPOSE

To determine the nature of problems threatening confidentiality between patients and physicians, particularly through demands of third party interests.

AREAS OF CONSIDERATION BY THE TASK FORCE

Confidentiality and Insurance Coverage for Psychiatric Patients

The Task Force on Confidentiality as Related to Third Parties (TFC) began conferences with Medical and Claims representatives of the insurance industry to study their legitimate needs for information and to examine with them the nature of psychiatric illness and treatment processes. Efforts were made in an attempt to reach an accord on the following aspects of this problem.

New Code System. One important achievement of the TFC was the formulation of a new code for reporting psychiatric conditions to third party agencies for health insurance claims. The TFC met in May, 1971, with various insurance agency representatives, including a committee of medical directors (Life Insurance Medical Directors of America, LIMDA) and the Health Insurance Council (HIC). As a result, a new reporting system was designed using a specific code aimed at fulfilling insurance agencies' needs while not revealing unnecessary information which could be misused or otherwise be damaging.

This new system of reporting was presented to the Council on Professions and Associations before being sent to all the District Branches in the U. S. and Canada for their examination and comment. Generally favorable and constructive suggestions were made, with the exception of a few that unrealistically advocated sending no information at all. Following discussion by the Council, the Reference Committee and the speaker of the Assembly of District Branches and representatives of the Health Insurance Council arrangements were made and are currently underway for an actual trial in the field. (A copy of the working code system is attached as Appendix B.)

Methods of Reporting to Insurance Companies. Much of the need for information by the industry is for the administration of the insurance contracts. Reimbursement of medical expenses and disability payments, etc. depend on the nature and detail of different insurance contracts. There may be certain exclusions, and the date of onset is also important. For instance, benefits usually are limited to

Task Force Report 9

actual onset during the period of employment. Another factor is the need for certain detailed data for the insurance company's actuarial department in determining risk factors in setting future premiums, and for predicting how much money would be set aside for reserve for claim payments.

Basic information required. It is the opinion of the Task Force that insurance carriers could reasonably expect the provider (the treating psychiatrist, in this case) to supply the following information:

1. Recognition that a psychiatric condition does exist. (In place of diagnosis, the new proposed code system would be used.)
2. Approximate date that patient recognized symptoms and need for treatment, when asked "date of onset". (Note that Task Force is recommending that patients supply this, requiring review by the treating psychiatrist.)
3. Nature of treatment in general terms.
4. Billing which shows frequency, cost of treatment, and whether office, home, or hospital treatment, to support fees charged.

It was agreed by the insurance industry representatives that when they need additional information, the medical director of the insurance company would write specifically to the physician involved asking specific questions and giving the reasons for needing this additional information. *The physician would not be in receipt of a form letter mailed by a clerk who has no knowledge of the problem.* In addition, it was agreed that the reply to the letter would go directly to the medical director under his safeguarding of confidentiality.

Limiting information given to the employer. The common practice, particularly in employer-linked insurance coverage, of forwarding sensitive information to employers was faced. This has been one of the most embarrassing and sometimes destructive abuses of confidentiality that our Task Force faced. Misuse of this personal and, at times, compromising material could have deep impact on an individual's career, social, or personal life. Awareness of such a danger, has, in many instances, deterred individuals from seeking psychiatric help, even though this was a provision of the plan. This issue was extensively discussed in our May, 1971, workshop with the LIMDA, and, on a number of occasions with the HIC representatives. We met with the Medical Relations Committee of HIC in July, 1973, and this concern was reiterated. In our discussion with representatives of the Health Insurance Council, they agreed to seek methods of quarterly experience reports to employers that would omit any identifying data concerning the employee or employees involved in creating the expenses on the program. The industry indicates they are required to make such reports to employers to justify premium charges. They

CONFIDENTIALITY AND THIRD PARTIES

were not able to justify having to supply the names of the employees involved. We had adamantly maintained a position that given all the arguments from the insurance industry, employers have no need for and should receive no data that can be identified with a specific known employee. The problem of employer administered programs was discussed. They are a major source of patient information reaching the employer. As a result of our discussions, the AMA and the insurance industry have published agreements to discourage and hopefully to eliminate such programs eventually.

Life insurance examinations limited to non-therapist physicians. The point was stressed with the insurance representatives that, if at all possible, examination and reporting for life insurance eligibility be done by a physician other than the treating psychiatrist. The insurance representatives could understand that such a request for information could jeopardize psychotherapeutic relationship.

Concern with storage of sensitive information within the industry itself. There has been considerable concern and question about insurance data banks, where allegedly confidential information is shared with other companies or organizations without patients' knowledge or consent. Although insurance industry representatives deny that this is a problem, documented cases have been received of instances of information being leaked accidentally or otherwise to patients and their relatives, of questionnaires requesting irrelevant information, and of use of the Retail Credit Bureau to investigate claims. Although HIC has given assurance that the RCB holds such information inviolate, complaints have been received that such investigations have included questioning neighbors about the nature of illness, thereby disclosing that the patient has been in treatment and even hospitalized. Some complaints also indicate that health care data acquired for claim payment has been shared with other insurance companies for other purposes.

Local Programs. Particular attention needs to be paid to the local administration of specialized insurance operations, such as CHAMPUS, an insurance program for the dependents of service personnel. The Task Force has been concerned with limitations which need to be instituted regarding the information made available to central and clerical personnel and in one instance successfully intervened when a Blue Shield organization attempted to force compliance with a request to photocopy psychiatric records on CHAMPUS claims.

"Consent to Release Information" Statement.

Present forms are not informed consent. The Task Force has had great concern with the blanket release of sensitive information,

Task Force Report 9

which has been the result of previous release policy. The patient often is not aware of, and therefore has not given informed consent to, the possible consequences of signing many of the present release forms. This is true also of the current AMA-approved changed form that differs in language, but not legal application, from the previously approved version. ("I hereby authorize the release of any medical information necessary to process this claim".)

The Task Force again stated its objection to the consent statement on the basis that it is not informed consent for the following reasons:

1. The patient does not know what is going to be released.
2. There is no limitation as to whom the information may be distributed once it is released.
3. There is no limitation as to what is considered necessary, nor who determines that.
4. It does not limit sources of information that then may be used for obtaining this vague concept of necessary information.

Limitation on information release. The Task Force recommends that the APA adopt a position approving forms only if the consent to release information is limited to a specific recipient, a specific purpose, and a specific time (in place of the current blanket release). There actually is nothing to prevent the patient from adding restrictions to a consent form if the basic information needed by the insurance carrier is kept in mind as mentioned above.

It was further recommended that the APA adopt a position encouraging its members to refuse to channel any sensitive information through employers, and that reports to medical directors of insurance companies be noted, "Any divulgence to other parties or for any other purpose will constitute a breach of confidentiality and of medical ethics".

National Health Insurance. Task Force investigation showed that none of the National Health Insurance plans had machinery for limiting the accumulation of medical data, nor for its protection from misuse. The APA issued a position paper for correcting this oversight in December, 1971. (This is attached as Appendix C.) Our Task Force carried this to certain Senators and Representatives. This resulted in a strong section on confidentiality in the law establishing the Office of Drug Abuse. This, in turn, had effect on Senator Ervin and the Subcommittee on Constitutional Rights in their work on medical data banks and abuse of privacy. Also, a section on confidentiality was included in HR 1 (the bill which created the PSRO's in the Social Security program) as a result of these efforts. Plans were suggested for broader study of this problem. The Task Force estab-

CONFIDENTIALITY AND THIRD PARTIES

lished machinery to deal with these problems through legislative offices, as well as local levels when indicated.

These were two principles that the Task Force felt should be stressed. First, data required to assure an individual of medical care should be separated from the more complete and personal data needed for statistical purposes, administration or research. And, secondly, the data recorded should be protected from dissemination or misuse. Confidentiality of research data will depend on the mechanism and persons controlling the information machinery.

Legal Aspects of Confidentiality as it Involves the Courts.

Federal Codes of Evidence — Rule 504. Although many states have clear protection for physician- and/or psychotherapist-patient communications as part of their evidence codes thus creating privileged communication, the future of the protection in the federal courts is less certain. Recently, the Federal Codes of Evidence have been under the process of revision, a step that requires Congressional approval of the final code. Initially, all medical privilege was excluded. Then, psychotherapist privilege was reinstated.

The Task Force on Confidentiality initiated conferences with legal authorities to study the problems involved, which led to developing grounds for improving the protection. The information developed and the contacts made were used via some District Branches and their Congressional representatives to change the definition of psychotherapist to include all physicians treating "mental and emotional disorders". While this was desirable in itself, it became even more important in January, 1973, when the American Medical Association petitioned Congress to eliminate psychotherapist-patient privilege from the proposed code. Again, through the machinery established by the Task Force — working through state medical societies, their delegates to the AMA, and various legal authorities — the AMA reversed itself, and so notified the relevant Congressional committees. The Louisiana District Branch was particularly important in these endeavors. The proposed code is being evaluated by Congress, and will be rewritten.

This threat to elimination of this protection has been diminished, but is not absent and the need to strengthen the protection as noted originally still exists. (See Appendix G.) Congress later did eliminate Rule 504, but some senators advocate that it be restored.

Confidentiality as it involves the military drug-abuse program.

In response to a formal request by Senator Harold Hughes for a statement from the APA concerning the effect of the confidentiality or lack of confidentiality in treatment and rehabilitation program for

Task Force Report 9

drug users, our Task Force has prepared a draft of a position statement for the American Psychiatric Association, presented in Appendix C. The statement was prepared after extensive discussions with persons involved in various aspects of such programs. The statement has three major thrusts:

1. A nonpunitive program must be truly nonpunitive, and volunteering for the program should grant protection for a confidential evaluation and on-going participation.
2. Medical records should be held inviolate in the medical treatment sector.
3. The patient's confidentiality should not be breached to civilian sources through the use of identifying codes, or through the comingling of personnel and medical records upon separation from the service.

The preparation of the draft of the Task Force report, and contacts which were established with appropriate offices, had positive effects on the preparation of the regulations which were proposed by one of the three military departments. The Department of Defense has now decided to alter the use of SPN numbers to code behavior disorders among other items of reasons for discharge from service. These will no longer appear on any of the discharge papers available to the ex-military person or to employers. Reasons for discharge will be kept more securely in classified files.

We would recommend the acceptance and publication of the current draft of the position paper, and continued ongoing contact with the Department of Defense in regard to these issues.

Computer Bank Information and the Need for Increased Protection of Confidentiality.

It has become apparent from numerous sources that there are in existence data banks which contain sensitive medical information for purposes ranging from insurance to national security. This trend would seem to require immediate, positive steps to provide mechanisms of protecting confidential medical data.

The Task Force has always urged upon the American Psychiatric Association that it consider the problem an ongoing one, and adopt an active approach to coping with it.

In the fall of 1973 the Task Force in a report to the APA Council on Professions and Associations spelled out the need for a conference to consider "gathering, storing, and retrieval in information systems that would safeguard constitutional rights as well as the medical need for confidentiality and the privacy of the individual". We noted at the time that "the problem is getting out of hand, and that

CONFIDENTIALITY AND THIRD PARTIES

the longer there is delay, the greater will be the problem in trying to institute a more acceptable system than is now growing by chance at its current explosive rate".

Happily, the sense of urgency of the Task Force received the sympathetic attention of then APA President, Dr. Alfred M. Freedman, the Medical Director, Dr. Walter E. Barton and others, who called together a representative group of national organization people to explore their common interests in this problem area. This led to more formal organization of a planning group, on which the Task Force Chairman served, to plan a major working Conference on the Confidentiality of Health Records with the cooperative participation of about 50 national organizations and agencies, representative of organized medicine and all of the major medical specialties, the insurance industry, law, hospitals, nursing, medical record keeping, behavioral science, consumer groups, government, and many others. The need for consumer groups to participate in such efforts was paramount.

The Conference was held at Key Biscayne, Florida, November 6-9, 1974 after about six months of preparation in which many of the participating experts prepared working papers of high quality that were sent out to all participants in advance.* Approximately 110 persons were in attendance.

A full report of the important conference will be published by the Association in the spring of 1975. However, the most auspicious single result of the meeting was the unanimous resolution of all participants (with two abstentions) that there should be formed an independently incorporated body tentatively titled National Commission on the Confidentiality of and Access to Health Records to serve the following purposes:

1. To promote and preserve the confidentiality of health care records and to establish guidelines and recommendations for appropriate access to them.
2. To propose legislation and regulations to study and analyze legislation and regulations, in formation or already introduced, and to make recommendations for action and implementation by sponsoring organizations.
3. To engage in educational activities serving as an information exchange between participating organizations, to develop and/or disseminate materials for public education on confidentiality and

*The Task Force Chairman, Dr. Grossman, notes: "This is an outstanding example of the combined efforts of a Task Force, working through Councils and the APA Reference Committee, supported by officers and trustees, having a major plan brought to fruition through the dedicated efforts of the APA staff."

Task Force Report 9

the access of records and to serve as spokesman for the adoption of guidelines and policies relating to these matters.

4. To develop through surveys and special studies methods for improved handling of health care information that will provide for appropriate access and preserve confidentiality.
5. To accomplish other appropriate objectives not inconsistent with those enumerated, by any lawful and ethical means.

In December 1974, the trustees of the Association voted unanimously to support the National Commission which is now in the process of formation under the aegis of an Interim Organizing Committee comprising representatives of the APA, American Academy of Pediatrics, American Medical Records Association, American Hospital Association, Mental Health Law Project, and the National Association for Mental Health. It is anticipated that the new Commission will be incorporated and fully underway before the end of 1975.

RECOMMENDATIONS REGARDING EDUCATION COORDINATION WITH OTHER AGENCIES, AND THE NEED FOR AN ONGOING GROUP

Education concerning the problems of privilege and confidentiality should be made available in various areas.

Inservice Education Within the APA Structure.

It would be helpful if the councils, committees and task forces dealing with areas related to privilege and confidentiality were informed of the findings and progress of this Task Force. Such action would add to the coordination of the efforts of the APA in safeguarding confidentiality of sensitive medical data.

Inservice Education to All Psychotherapists.

We would recommend that the APA publish a pamphlet to cover such topics as the difference between privilege and confidentiality, how to respond to a subpoena, appropriate methods of record keeping that will preserve confidentiality, and an explanation and a description of how to use the new coding system, were it adopted, for reporting to the insurance industry.

Education to the Lay Public.

Through the lay press, the APA should attempt to clarify physician-patient privilege, confidentiality, and the importance of these concepts.

Coordination with Other Agencies.

Developing insurance forms and coding mechanisms which protect confidentiality. Coordination with the Health Insurance Council and other groups of the insurance industry will be critical for the potential success of the proposed coding scheme. Excellent contacts have been established with these organizations, but continued effort will be necessary so that there can be no question as to the importance attached to confidentiality by the psychiatric profession and to our concern that confidentiality must also become important to the

Task Force Report 9

health insurance industry. These efforts could be furthered with involvement of other medical organizations, including the American Medical Association.

Workshop dealing with data banks. Our discussions with representatives of various organizations have convinced us that such a workshop should involve the American Psychiatric Association in effective collaboration with a number of other groups. Through involvement of groups, including other medical organizations and representatives of the insurance and data processing industries, as well as consumer organizations, we would hope to increase the likelihood of effective legislative action which would aid patients who seek psychiatric help.

Need for a Specific Ongoing Group within the APA Concerned with Confidentiality and Particularly with Confidentiality and Third Party Payment.

The rapidity of developments involving confidentiality and third party payment, their complexity, and the needs for continuous active involvement for satisfactory resolution, prompt our conviction that a specific group within the APA be charged with responsibility for issues involving confidentiality. It is our belief that the activity would require a long-term group with both "watch dog" and active corrective force, with the strong backing of the APA.

In an immediate phase, the active negotiations in which the current Task Force is involved with the insurance industry are still in a delicate period with the outcome extremely promising but by no means certain. These extensive activities and contacts with the relevant aspects of the insurance industry must be furthered and continued by an ongoing group of the APA, in an atmosphere of mutual respect with the insurance industry, but with firm concern on the part of the APA group for the needs of the patients, both current and potential.

The current Task Force has accumulated a great deal of information regarding desirable and undesirable practices in relation to the insurance industry, and plans over the coming year to convert that material to monograph form. Consideration of the evolving practices of third party payment and their implications for psychiatric treatment with regard to confidentiality should be an active part of the role of an ongoing group.

Contacts with members of Congress have proved to be extremely helpful to the current Task Force and should continue to be so for any ongoing action group of the APA. Congress passed and the President signed S-3418 into Public Law 93-579 December 31, 1974,

CONFIDENTIALITY AND THIRD PARTIES

The Privacy Act of 1974. This protects personal data in Federal agencies and creates a seven-member commission to explore similar problems in other governmental and private areas.

We believe that a separate group in the APA should be formed concerned with confidentiality, and that the task should not be divided among a number of groups which also have other responsibilities. The area of confidentiality is extremely topical, represents one of the most direct ways in which psychiatrists can aid their patients in the non-therapeutic situation, and requires the considerable effort that only a vigorous, single-focused group can provide.

ACKNOWLEDGMENTS OF THE TASK FORCE CHAIRMAN

The Chairman would particularly call attention to the active work of Kenneth A. Ritter, M.D., of New Orleans; Jerome S. Beigler, M.D., of Chicago; Morton R. Weinstein, M.D., of San Francisco, Jean Craton-Neher, M.D., of Palo Alto, California and James M. Trench, M.D., of Hartford, Connecticut; among many individuals who worked actively in whatever we accomplished on the national scene.

Special credit should be given to Dr. Richard Johnson for the formulation of the Type I-VI Coding, and for the chronology and detailed reporting of our activities which has made it easier to compile this report; and to Frank M. Ochberg of H.E.W. for valuable suggestions.

The help of Central Office from Walter Barton, M.D. and his staff in counseling and cheerful cooperation not only made it possible for us to function, but added to the pleasure we derived from our task. As Chairman, I can only state the obvious, that my co-workers on the Task Force were all a dedicated, hard-working group. Their individual inputs balanced extremely well in reaching an aggressive, action-oriented approach, but still tempered with reason.

APPENDICES

Appendix A: General Principles Governing Confidentiality

1. Every person has a basic right to the pursuit of health and happiness, and privacy is a necessary prerequisite for this.
2. Psychiatric practice cannot properly achieve maximal effectiveness except where there is a secure atmosphere of confidentiality.
3. We are, together with the patient, chief advocates of an affirmative atmosphere of confidentiality.
4. Any authorized release of information to a third party should be made only after full discussion with the patient.
5. Only the minimum information required to meet legitimate needs should be released.
6. We should never collude with the patient in making false representation to a third party.
7. In rare and special cases where danger to persons, self, or others is imminent and can no longer be handled in the context of treatment, our obligation to society requires that we break confidentiality, but only to the minimum extent necessary to protect life or property.
8. The psychiatrist has the responsibility to determine whether disclosure of information to family members or other third parties will work for or against the patient and his treatment.
9. The boundaries of disclosure to third parties should be determined with the patient in the early stages of treatment.
10. Blanket consent for release of information is never satisfactory. Patients should give specific consent each time for each disclosure to each third party; informed consent should be limited to the specific purpose at issue and indicate that it is time limited for the purposes of the claim.
11. Insurance companies and other third parties have a legitimate right to certain information about a patient and his treatment.
12. Information should be released in a way that will promote the best interests of the patient and in such a way that it cannot be used against his best interest.
13. Information released to meet a legitimate need of a third party should be held in confidence by that third party. Such information must not be re-released to other third parties without the specific consent of the patient.

Task Force Report 9

14. No person should be penalized by his insurance company because of receiving treatment.
15. Insurance cost accounting should always be made in aggregate without reference to confidential information concerning individuals.
16. Eligibility to obtain insurance or employment should be determined by examination for that purpose, not by reference to information from treatment.
17. National Health Insurance laws must have specifically detailed outlined legislative safeguards for the protection, gathering, storage, retrieval and distribution of data about patients, and not be cloaked in general terms.
18. Schools and employers should get information about treatment only when such release is in the interest of the patient and must take into account that the patient's condition is subject to improvement. School and work records reflecting treatment must therefore not brand the patient unfairly with no longer current information. Furthermore, such records should be destroyed after an appropriate short interval.
19. We should apply these same general principles to the problem of privilege, which is a separate and distinct sub-category of confidentiality.
20. We should work for the strengthening of laws and procedures to protect privilege, confidentiality, and the privacy of our patients and to secure the support of the public including our patients in this effort.

Appendix B: Proposed Coding for Mental Disorders

The realities of current and future health insurance coverage for psychiatric treatment will include the need to report some justification for the treatment, whether for hospital costs or physicians' services. In the past, using official diagnoses often led to the demand for completing detailed questionnaires plus repeated experiences of breach of confidentiality that were destructive both to the patient and the treatment process. Efforts have been made to demonstrate to the insurance industry that other forms of reporting might better serve the needs of our patients while meeting the needs of the industry more effectively.

The Coding System which is listed below has been formulated to divide reportable conditions, not due to physical or organic factors, into six general categories. These categories represent a synthesis of diagnosis with varying degrees of impaired function. It is for that reason that some diagnostic categories appear in more than one of

CONFIDENTIALITY AND THIRD PARTIES

the six designations. The category type may possibly be changed in later evaluations as the clinical function of the patient changes.

Insurance reports would merely signify "Category I (or II, III, IV, V, or VI)" instead of DSM II diagnosis and code number which should be kept in the doctor's confidential file. This private evaluation would be available only under proper safeguards to peer review colleagues or to the Medical Director of the carrier. Such reports would go directly to the Medical Director and not through ordinary channels and would be protected by the medical ethics of the Medical Director.

We recognize that the insurance industry needs certain data for actuarial purposes. However, the extensiveness of treatment required and choice of treatment approaches can not be indicated by diagnosis alone. It is suggested that in reporting, the nature of proposed treatment be made available to medical representatives of the insurance carrier and any question about the appropriateness of the intensity or duration of treatment be referred to peer review process.

A criticism from the insurance industry is that conditions in Category I would indicate no need for compensable treatment. This overlooks the factors of anxiety and/or depression liberated by such conditions. At the minimum it would require a diagnostic interview.

In general, the code tries to convey the general nature and seriousness of the condition at the presenting time of the report. While prognosis might be inferred, it cannot be specifically determined from the code number used. It is assumed that inquiries from the insurance carrier will be made by their Medical Director for a specified, concrete purpose. It is expected that this would not be a frequent occurrence, and under no circumstances be made available to any other party, nor even to the patient.

Proposed Coding For Mental Disorders

- A. *Mental Retardation.*
- B. *Mental Disorder associated with physical or organic factors.* (Would suggest the nature of the physical or organic factor be reported in general terms, e.g., endocrine, infectious, circulatory, tumor, etc.)
- C. *Mental Disorder currently considered of psychogenic origin.*
 1. *Acute Situational* (basically healthy personality reacting abnormally to stress situation.)
 2. *Characteriological or Emotional* with fair adaptation in most areas (e.g., mild neuroses or character disorders, etc.)
 3. *Characteriological or Emotional* with less adequate adapta-

Task Force Report 9

tion in some areas (e.g., oral type character disorders or neuroses, etc.)

4. *Characteriological or Emotional* with poor adaptation in some or involving many areas (e.g., infantile type neuroses or character disorders, and some forms of psychotic reactions, etc.)
5. *Severe Emotional Disorder* with poor or no adaptation in one or more crucial areas of functioning (e.g., extremely severe neurotic or psychotic syndromes.)
6. *Most Severe Emotional Disorder* with poor or no adaptation in enough areas to require constant supervision and not responding to continued, active psychiatric treatment (e.g., totally withdrawn psychotics, totally incapacitated conversion hysterics, some character disorders, etc.)

It is recognized that most patients cannot clearly fit a *text book* picture. The category selected will depend on the judgement of the psychiatrist considering all factors that pertain to any specific patient. The above examples are just that and are not intended for determining any one specific case designation. Similarly, the comparison below of the Type Codes to the DSM II Manual of Diagnoses is to be considered in like manner.

DSM II Breakdown for the Above Codes

Category I Acute Situational

Transient Situational Disturbances

307.0—307.4 Adjustment reaction of infancy, childhood, adolescence, adult and later life

Social Maladjustment without manifest psychiatric disorder

316.0 Marital maladjustment
 316.1 Social maladjustment
 316.2 Occupational maladjustment
 316.3 Dyssocial behavior
 316.9 Other social maladjustment

Category II Characteriological or Emotional Problem with fair adaptation, but with interfering symptoms requiring treatment

Neuroses

300.0 Anxiety
 300.1 Hysterical
 300.4 Depressive (reactive)

 CONFIDENTIALITY AND THIRD PARTIES

Personality Disorders

- 301.5 Hysterical
 301.4 Obsessive Compulsive (less severe symptoms)
 NOTE: A good example where treatment can be
 difficult and long.

Behavior Disorders of Childhood and Adolescence (any of the less severe behavior problems in an otherwise apparently healthy young person)

- 308.0 Hyperkinetic reaction
 308.1 Withdrawing reaction
 308.2 Overanxious reaction
 308.3 Runaway reaction
 308.4 Unsocialized aggressive reaction
 308.5 Group delinquent reaction
 308.9 Other reaction

Category III Characteriological or Emotional Problems with less adequate adaptation in some areas

Neuroses

- 300.13 Hysterical, conversion type
 300.2 Phobic
 300.3 Obsessive compulsive (with more disabling symptoms)
 300.4 Depressive (with more interference with functioning)
 300.5 Neurasthenic
 300.7 Hypochondriacal

Personality Disorders

- 301.1 Cyclothymic (moderate)
 301.2 Schizoid
 301.3 Explosive
 301.4 Obsessive compulsive (more severe)
 301.6 Asthenic (moderate)
 301.81 Passive aggressive
 301.82 Inadequate

Sexual Deviation

- 302 Series as listed (less severe problem with basically good ego strength)

Task Force Report 9
Alcoholism

303.0 Episodic excessive drinking (addiction not clearly established)

Drug Dependence

304 Series as listed (less severe and with good ego strength)

Psychophysiologic Disorders

305 Series as listed (less severe with basically good ego strength)

Special Symptoms

306 Series as listed (less severe speech disturbances, tics, etc. with basically good ego strength)

Behavior Disorders of Childhood and Adolescence

308 Series as listed (more severe and in more troubled personality)

Category IV Characteriological or Emotional with poor adaptation in some or involving many areas

Psychoses

295 Schizophrenia series as listed, with some social functioning

296 Major affective disorders series as listed, with some social functioning

Neuroses

300.14 Hysterical, dissociative type

300.4 Depressive (severe but not psychotic)

300.5 Neurasthenic (severe and chronic)

300.6 Depersonalization

Personality Disorder

301.0 Paranoid

301.3 Explosive (severe with poor control)

301.7 Anti-social (severe)

301.82 Inadequate or infantile (marked)

Sexual Deviation

302 Series as listed (more severe problem with poor ego strength)

CONFIDENTIALITY AND THIRD PARTIES
Alcoholism

303.1 Habitual excessive drinking

303.2 Alcohol addiction

Drug Dependence

304 Series as listed (if chronic, severe, and in a troubled personality)

Special Symptoms

306 Series as listed (if chronic, severe, and incapacitating; e.g., anorexia nervosa)

Psychotic Reaction

Short-term break with reality in otherwise fairly well integrated personality

Category V Severe Emotional Disorder

Neuroses

300 Series as listed, unable to function in a crucial area, but showing change in treatment

Schizophrenia

295 Series as listed, unable to function in one or more crucial areas, but showing response to treatment, and with history and onset suggesting some favorable possibilities

Major Affective Disorders

296 Series as listed (with some qualifications as under 295 in this category)

Category VI Most Severe Emotional Disorder

Any chronic neurotic, characteriologic, or psychotic disorder so poorly adapted that constant supervision is necessary, and having shown no response to previous active, continued treatment, but will require symptomatic treatment or constant supervision.

Examples of coding as noted above, many factors may be determined by the reporting psychiatrist that cannot be foreseen in such a generalized plan. He will obviously use his judgement as to how a specific patient fits the general intent of the Code system. The use of DSM II is dictated by it being the one officially adopted by the APA, and does not represent any judgement on its general acceptability. Again, it is being used to give some suggestions how the Code system might be

Task Force Report 9

applied. It might be well to repeat that, whatever basis for using a Code number for any specific patient is used, it should be recorded in the psychiatrist's own records, since some form of peer review will probably be instituted. Some examples follow:

1. A brief emotional crisis period might be resolved in one interview, or the severity of the symptoms might require a brief period of intervention for the patient to cope with the crisis and regain his equilibrium. It might be diagnosed "307.3 — Adjustment reaction of adult life." It could then be coded "I". If the same crisis really provoked an underlying neurosis, but with good reintegration, it could be coded "II."
2. A mild reactive depression which in DSM II is coded 300.4, Depressive Neurosis, could use code "II."
3. A patient whose depression was more severe, but not psychotic, could have the same DSM II diagnosis, but be coded "III."
4. Making a diagnosis of 301.81, Passive-Aggressive Personality Disorder, with enough interference in functioning could be coded "III."
5. A patient diagnosed Schizophrenic could be coded "IV," "V," or "VI," depending on the severity and interference of the symptoms, the nature of the onset, the response to treatment, or the chronicity and failure of responding to treatment; so could a "paralytic" conversion hysteric who had been neglected.

If, in special instances, the hazard to the patient of disclosure is exceptional, this should be made known to the Medical Director of the insurance carrier and the necessary information made known directly to him.

Appendix C: Position Statement on the Need for Preserving Confidentiality of Medical Records in Any National Health Care System

*This statement was approved by the Board of Trustees of the American Psychiatric Association on October 1, 1971, upon recommendation of the Task Force on Confidentiality as It Relates to Third Parties.**

Many approaches to establishing a national health care system are now being considered. Whatever system may eventually be adopted will inevitably entail the collection of intimate and private

*The task force included Maurice Grossman, M.D., chairman; Jack D. Barchas, M.D.; Richard G. Johnson, M.D. and Joseph Satten, M.D.

 CONFIDENTIALITY AND THIRD PARTIES

medical, psychological, and social data concerning those who use it. How these data are utilized can have a tremendous impact on the privacy and lives of identifiable individuals and, collectively, on the entire body politic. Protecting the confidentiality of medical disclosures is especially imperative for those who need and obtain psychiatric treatment, as has already been recognized, e.g., by the laws of many states, in court decisions, and in the drafting of the code of evidence for the federal judiciary.

Two separate bodies of data will be collected.

The first will include identification of the individual in the process of establishing eligibility for treatment and in reporting the treatment process. In our view the confidentiality of these data can be safeguarded by limiting the information disclosed to the least amount necessary for establishing eligibility and by developing methods to control overusage of the system. Review of such identifiable data, if it is necessary at all, should be minimal, and the availability of the data should be confined to carefully selected personnel at the treatment site. Under no circumstances should the data be duplicated and recorded elsewhere or rendered available to groups that are not connected with the treatment situation. The data should be used only to facilitate the treatment process.

The second group of data will be needed for program review, for the evaluation of the efficacy and efficiency of the system, and for medical and administrative research. These data will be computerized.

In the case of program review and evaluation, it will be vital to protect the identity of the patient with reference to the data that are collected and stored. (There can be no objection to identifying providers, individual or group, for whatever review is needed.)

However, medical research will entail the collection of much intimate data on the individual; this will require careful planning concerning how the material is to be stored and who will control accessibility to the data and for what purposes. Specific legislation governing these matters must be carefully framed if the confidentiality of the records of the individual patient is to be fully protected.

The framers of national health care proposals should be fully cognizant of the imperative need for safeguarding the confidentiality of medical records in the contexts described here.

*Appendix D. Position Statement on
The Role Of Confidentiality In Volunteer Military
Drug Abuse Treatment Programs*

The American Psychiatric Association was much encouraged and

Task Force Report 9

pleased when the President and the Department of Defense adopted a policy of viewing the drug abuser as a medical problem, while still maintaining its efforts to eradicate the traffic in drugs. A treatment program written by the military establishment must be seen as positive action directed toward furthering the primary mission of the armed forces.

The role of confidentiality in successful psychiatric treatment has been well established. The development of a positive treatment atmosphere for a voluntary rehabilitation program for drug abusers is partially contingent upon the degree to which a psychiatrist can assure the patient of the confidentiality of his disclosures. The real or threatened adverse consequences of disclosure may cause personnel to avoid seeking treatment altogether or not to cooperate fully in the treatment regime.

As civilian psychiatrists, we can only recommend those things concerning confidentiality which we feel will help lead to an effective voluntary military drug abuse treatment program. In any program offering confidentiality, the limits of confidentiality must be defined. Any promise of nonpunitive action must truly be nonpunitive; otherwise, subsequent disillusionment of the treated person will create destructive reaction to both his treatment and the program in general. There have been examples of previous unsuccessful treatment programs where the limits of confidentiality were not well defined and, indeed, did not prevent secondary punitive action from taking place. This protection for those honestly seeking help will provide a more effective program and increase motivation for help.

The act of volunteering should only grant protection for a confidential evaluation prior to acceptance into the drug abuse treatment program, and for ongoing participation and cooperation in the program. In recommending this amnesty, we do not imply that personnel in treatment are immune from consequences of unacceptable behavior secondary to or not related to the fact of treatment.

Being labeled a drug abuser is punitive in itself. For that reason, as far as possible, all medical records of treatment should be held inviolate in the medical treatment sector. In military programs, as in civilian programs, both the patient and psychiatrist recognize that, at times, for various reasons, this confidentiality cannot be absolute. The medical unit and command unit must be aware of each other's needs and responsibilities, and adequately keep each other informed of factors that would represent a hazard to the treatment of the individual or to the command's mission. (Army regulation AR-40-42 is an existing example of these safeguards.)

There are three special considerations brought to our attention that could also seriously and adversely affect the viability of drug

CONFIDENTIALITY AND THIRD PARTIES

abuse treatment programs:

First, compromising conditions for entering the treatment program should be avoided. For example, making amnesty or treatment conditional on the individual becoming an informer will seriously affect the credibility of the program. (The Army has taken note of this in Army regulation AR-40-42, paragraph 6G, which specifically deals with this point.)

Secondly, there have been reports of damaging breaches of the patient's confidentiality by critical information being released to civilian sources after discharge from military duty. One way of exposing individuals in drug treatment programs after separation from service has been the SPN number on discharge papers. We would urge re-examination of the policy of using these SPN numbers on discharge records that are not kept in confidential military medical files.

The third consideration is the intermingling of general personnel records and medical records at the National Personnel Record Center after separation from service. These medical records have been made available for other than military uses after personnel have returned to civilian life. For protection of confidential information, we would recommend an exploration of methods to separate from personnel records the medical records and references to medical diagnoses.

We are pleased that the Department of Defense is already considering the problem of confidentiality and we hope these comments will be of use in the implementation of its programs.

Proposed by the APA Task Force on Confidentiality
as Related to Third Parties

Maurice Grossman, M.D.
Richard G. Johnson, M.D.
Joseph Satten, M.D.
Jack D. Barchas, M.D.
Alan L. Krueger, M.D.

*Appendix E: Recommendations Of The Task Force On Confidentiality
As It Relates To Third Parties To The Council On Professions And
Associations, October 1971*

1. That APA adopt a position recommending its members limit information to insurance companies for health care reimbursement to the following:
 - a. Recognition that an unspecified psychiatric condition does exist (in place of diagnosis).

Task Force Report 9

- b. Approximate date that patient recognized symptoms and need for treatment (or onset).
- c. Nature of treatment in general terms.
- d. Billing which shows frequency and cost of treatment.
- e. Billing which shows whether office, home, or hospital treatment — to justify fees.

If any of the above proves discriminatory in special situations and information is withheld, peer review should be offered. (The IBM system demonstrates it can work.)

- 2. That APA adopt a position recommending its members refuse to channel any sensitive reports through employer agencies; and that reports to medical directors of insurance companies be noted, "any divulgence to other party or for other purposes will constitute a breach of the release waiver and of medical ethics."
- 3. That APA adopt a position that the reports for life insurance applications be obtained from examinations for that purpose and not from psychotherapists.
- 4. That APA adopt a position approving forms only if waiver to release information is limited for specific agent, specific purpose and time, (in place of current blanket release) with notation given in #2.
- 5. That APA pursue these proposals with the AMA to get their support for similar position.
- 6. That APA encourage Congress to write in safeguards for confidentiality as an integral part of the plan in whatever bill for national health care finally evolves.
 - a. Some forms of coverage automatically obviate any need of information to support treatment availability.
 - b. Confidentiality of research data will depend on the mechanism and persons controlling the information "machinery."
 - c. "There is need to demonstrate and explain graphically the difference between its general medical model of treatment and the current model of psychiatric care in our present day status of the art." (Minutes of July 10-11 meeting).
- 7. That APA issue a statement supporting Senator Hughes' position on the impact of lack of confidentiality on the drug abuse program of the military (and eventually of the general civilian program).

CONFIDENTIALITY AND THIRD PARTIES

8. That APA commend the Commission of the Federal Judiciary for retaining Code 504—Psychotherapist-Patient Privilege—BUT—
 - a. Request them to strengthen it by adding to definition of psychotherapist, "or any licensed physician treating an illness with emotional components as cause."
 - b. Request them to consider statement of psychiatrists' needs for protecting patients while defenses are down during therapy, to include version of Illinois law that extends the privilege to the psychotherapist as well; and that law's liberalization by deleting exceptions to the privilege.
9. That APA consider the suggestions from Louisiana, and notify its District Branches that the proposed Federal Code will be acted on in November; and that they enlist support of their congressmen to enact the above changes.
10. That APA consider, in any section of its code of ethics on maintaining confidentiality, NOT to include any exception, such as in AMA Section 9, "unless required by law," since being law abiding is a major ethic in itself. Further, that the APA discuss with the AMA the deletion of this phrase from Section 9, for reasons already given.
11. That APA undertake a sampling survey of its members to determine their attitudes on confidentiality and incidence of impairment in patients' welfare occasioned by released information or threat of such release.
12. That APA subsidize a sampling survey of the general public about their beliefs, how protected they are from physician disclosures, and whether it would affect them in any way.
13. That APA bring this problem to the attention of training centers, with the following goals in mind:
 - a. To emphasize to medical students and psychiatric residents their responsibility for confidentiality.
 - b. To teach them that record keeping must vary with purpose in mind, and awareness of ultimate fate of the records.
14. That APA elaborate its previously issued discussion of response to subpoenas, and issue it as a brochure with a description of the subpoena-issuance process and its implications, with specific steps to be taken at specific times.
15. That APA consider the need for "consumer" demand for such protection and explore ways of publicizing the problems. The current growing general unease about invasion of privacy of information could facilitate this.

Task Force Report 9

16. That the APA trustees secure legal counsel's opinion for the Task Force about:
 - a. Patient's blanket authority for release of information, especially in light of doctrine of enlightened consent, and substitution of limited consent form.
 - b. Some members' use of form to be signed by patients waiving their right to permit release of, or demand for, records.
 - c. Some members keeping no records, as way of defeating any demand for records.
17. That the trustees emphasize to all councils, committees, and task forces that some of their actions and recommendations might adversely affect the climate of confidentiality, and their recommendations should include safeguards to protect it.
 - a. Much of our discussion relates to the province of the Committee on Psychiatry and the Law, and our minutes have been made available to them.
 - b. Much of our discussion relates to the province of the Committee on Financing of Mental Health Care, and our minutes have been made available to them.
 - c. Reference has been made to problems that might concern Committee on Children and Adolescents. It is recommended that relevant sections of our minutes, especially of the July 10-11, 1971 meeting be brought to their attention.
 - d. The question of research records and confidentiality has been explored by another Task Force. Our Task Force is uncertain that reliance can be placed in ordinary governmental safeguarding of privacy.
 - e. The impact of lack of confidentiality on treatment programs should be considered by the Committees on Alcohol and Drug Abuse.
18. And, most importantly, that the APA seek funding for a project to explore systems of safeguarding data, while accumulating the valuable detailed information that will be available in a national health care program. Further, the APA should seek ways of using this data to better understand psychiatric illness, its nature, its sources, its response to treatment. One limited goal would be to seek a system of classification that would be meaningful for etiology, prognosis, and treatment. The recognition that this will require intimate individual identifiable data makes more pressing the consideration of safeguarding this data in the initial planning stages.

CONFIDENTIALITY AND THIRD PARTIES

*Appendix F: Principles Governing Confidentiality And Disclosures To Third Parties (September, 1973)***1. The Need**

There is a consensus in the psychiatric world, the legal community, and a general philosophy that psychiatric treatment requires a positive atmosphere of confidentiality to protect the patient's right to the pursuit of health and happiness (GENERAL PRINCIPLE I); and, even more important, to create that positive atmosphere of confidentiality that will encourage individuals needing help to seek that help without fear of destructive disclosure to the rest of the world. Less widely stated, but still recognized, is the fact that hazard to patients still exists in our social climate from disclosure of having been in treatment. Some diagnostic terms have discriminating social connotations and can cause injury to patients if made known to others. Although it is generally recognized that each patient is responsible for protecting his own rights, nevertheless, our relationship as therapists to those patients places us in the position of being their chief advocates for protecting their rights to confidentiality (GENERAL PRINCIPLE II). This need to be their advocate is increased when patients' ability to protect themselves is impaired by their psychological state or functioning; in states of temporary regression that may be incident to the therapeutic process; where patients give consent under duress; or where patients give consent, uninformed of the consequences of their consent.

It would be ideal if we could have that social state where all patients could freely, but safely, speak of their psychiatric illness and treatment. For them to be able to openly accept this would truly facilitate seeking and cooperating in treatment. Realistically we have not achieved that social state even though improvements have taken place. Attitudes of a large part of our social world are still prejudicial and the livelihood and social well-being of some of our patients can be threatened in reality by the disclosures mentioned above, apart from any neurotic fear of discovery. It is in recognition of the reality of this social state that this report has been formulated.

2. The Problem

Problems are created, however, when third parties have both a legitimate and an ethical right to some information about the patient, the treatment process, or even disclosures during the treatment process. We must differentiate between our obligations to the patients in protecting their privacy and the disclosures they have made to us for the purpose of treatment; and the need to recognize that information which legitimately should be disclosed to a third party, often with

Task Force Report 9

the patient's consent, for advantages that are important to the patient or conversely by reason of obligation to society that supersedes the patient's rights.

It would be just as destructive to the treatment process if we knowingly became a party to any manipulation of fact (as differentiated from withholding information because of confidentiality needs) (GENERAL PRINCIPLE III). For many reasons, it would be a breach of professional ethics; even more, it would be just as destructive to the psychotherapist-patient relationship in preserving the atmosphere of integrity necessary for effective psychotherapy. In general, whenever there is the problem of information to be released to any third party, it should be discussed with the patient beforehand, unless unusual circumstances make this impossible (GENERAL PRINCIPLE IV).

There are situations where a physician's obligation to consider hazards to society outweigh his obligation to preserve the privacy of the patient, even without his consent. These are usually when the patient and his behavior represent a clear and extreme danger to himself or others. Usually such crises are most frequently technical treatment problems. If possible, they should be worked out through treatment techniques. Also, outside consultation should be carefully considered. Once such resources have been sought and in the psychiatrist's judgment the patient represents an extreme danger to himself or others that cannot be contained therapeutically, it is necessary to notify others of the hazard for the protection of the patient or these others, and confidentiality should be broken to the extent necessary (GENERAL PRINCIPLE V).

3. *Special Situations*

There are special considerations that must be weighed in certain circumstances. Because of the growing involvement of third parties, absolute privacy in all situations is now a thing of the past, if it really existed beforehand. The problem is to minimize the effect of disclosure, on the treatment process, as it affects the patient, and as it affects other parties concerned with this privileged information. When information is to be divulged, it should be that minimum necessary.

4. *Family (And School) Requests*

The most common special situation is the request for information from family members. In many situations, discussing some of this information may actually help the therapy and directly and indirectly help the patient. It therefore imposes a burden on the therapist to decide whether disclosure operates for the patient or against

CONFIDENTIALITY AND THIRD PARTIES

the patient (FAMILY PRINCIPLE I). This same applies to information disclosed to school teachers and others in the school system during the treatment of children. In this latter situation the problem is complicated by the school personnel making written records of this information that eventually becomes out of date or is misused by others not having the opportunity of first-hand consultation with the therapist. Where the family is involved, there should be prior agreement among the patient, the family, and the therapist on the standards of confidentiality that will be applied (FAMILY PRINCIPLE II). Even when total withholding of information is practiced, the involvement of the family should not be ignored, and they should be helped with whatever support they might need in the situation. This is based on the reality that the emotional state of the family is going to have a direct effect on the patient and be a subsequent influence on therapy of that identified patient.

5. Insurance Reports

Requests for information from insurance companies and/or employers who subsidize insurance programs for treatment cost reimbursement have become the most frequent imposition on confidentiality, with proportionately grave interference with patients' welfare. Inasmuch as insurance coverage constitutes a contract limiting to some extent the benefits to which the patient is entitled, there exists a legal and ethical need to give others information to determine whether the treatment costs are within the boundaries of the contract. Foremost, any patient receiving care through any system of paying for such care should have access to all medical services without jeopardizing their privacy or their confidential relationship with their physician (INSURANCE PRINCIPLE I). This latter condition is a necessary component of effective treatment. Therefore, no system should jeopardize such effectiveness. Secondly, since the purpose of insurance is to minimize the risk and impact of calamities by spreading the risk, no patient stricken by illness in any form should be penalized because he has added "a burden" to the group load (INSURANCE PRINCIPLE II). The patient as an individual should have confidentiality protected by considering group experience in all cost accounting proceedings for whatever purpose.*

*Over 90% of health insurance coverage is through industrial group policies where all members of the group are blanketed in regardless of their state of health, other than excluding conditions whose onset antedated application of the contract. Some life insurance written on a group basis operates the same way with additional proviso that an examination is required for those over a specified age. Premiums are set to cover the statistical chance of poor, average, and excellent probabilities of morbidity or mortality. Even when added

Task Force Report 9

Because of the reasons given above, treating psychiatrists will have to give some information if their patients are to have the benefit of insurance coverage (INSURANCE PRINCIPLE III). This information would include that a psychiatric condition, unspecified, does exist to indicate that there is a medical condition covered by the contract. In some situations, only to demonstrate that the illness did not exist prior to a contract where the contract excludes such illness, it will be necessary to give approximate date of onset of the symptoms complained of by the patient. To substantiate the type and frequency of treatment given, it may be necessary to give some information indicating the general degree of unspecified impairment. Peer review would be preferable. The general nature and frequency of treatment might have to be recorded for billing purposes.

No information given in a written report for these purposes should be in language that could be construed in any way, by anyone, to defame the patient. If necessary, such information should go directly to a physician representative of the third party, preferably in verbal communication, with statements that such information is being divulged under ethical professional obligation of the recipient as well to maintain confidentiality. This has been acceptable to a number of insurance companies, but subject to peer review on demand. Under no circumstances should any sensitive information from treating physicians, required for insurance purposes as given above about an identified individual, be routed through or be made available to an employer (INSURANCE PRINCIPLE IV).^{*} Reporting to the employer for cost accounting purposes should be done on a group basis, without any identification of any patient creating any load on the system. Once this information has served the legitimate purposes given above, after medical evaluation of its application to the insurance contract, no further use should be made of this information in identifiable, individual recording or data storing. Since this will be even more complicated with the advent of national health care coverage,

premiums are demanded for known pathology risks, the same evening out by distribution operates. To then eliminate those who are unfortunate enough to develop costly medical problems overlooks the fact that some under the same contract may never develop illness requiring payment for treatment.

^{*}There are situations where an employer must be notified of circumstances developed in the treatment relationship to secure cooperation in therapy; or because the danger to society is greater than the obligation to the patient (see GENERAL PRINCIPLE V above). If this be so, the disclosure should be based on the general treatment situation and not incidental to insurance reporting. While some contracts demand processing of claim by employer, most carriers will accept report going directly to medical department of the insurance company. INSURANCE PRINCIPLE IV about employer access has been accepted by the AMA and the International Claim Association.

CONFIDENTIALITY AND THIRD PARTIES

and because there will be a storage of much individual intimate material, a separate policy statement on this has already been formulated. The essence of this statement is that we must separate minimized data needed to assure individuals' rights to care from the data needed for any statistical purpose of administration or research (NATIONAL HEALTH PLANS PRINCIPLE I). That data to be recorded for all purposes, the protection of the data once recorded, and the limitations of its accessibility should be an immediate and integral part of any initial plan for national health care coverage (NATIONAL HEALTH PLANS PRINCIPLE II).

6. *The Courts and Subpoenaed Information*

The first section of this position paper is especially applicable in court. The demand for information about our patients by courts or other governmental bodies via the power of subpoena presents special problems. Such demands are not as frequent as others, but when they occur, they can have a devastating effect on the patient and his psychotherapy. Recent developments have been more favorable to the protection of this information. This protection has been increased by judicial decision recognizing the importance of preserving this confidentiality, as exemplified by the California Supreme Court decision limiting disclosure to the bare minimum where exceptions to psychotherapist-patient privilege are written into the law. In that decision, they were quite explicit in stating that any further protection must come from legislative action, even though they recognized the seriousness of the existing threat.

The California Legislature, as did some other states, created the bulk of such protection in law in creating the act that provides psychotherapist-patient privilege. The exception that waived the protection for the patient litigant has been a destructive loophole as witnessed in actual court proceedings. The Federal court system was about to deny any protection, but finally in their proposed Code of Evidence incorporated a code similar to that in California.* Congress failed to accept this proposal. Illinois, which had a similar law, almost eliminated this exception entirely; but did modify it to improve the protection in divorce and child custody proceedings. This was accomplished through active efforts of the Illinois District

*Proposed Federal Rule 504 creating psychotherapist-patient privilege has three broad exceptions to this privilege. That labeled (c) reads: "Condition an element of claim or defense. There is no privilege under this rule as to communications relevant to an issue of the mental or emotional condition of the patient in any proceeding in which he relies upon the condition as an element of his claim or defense, or after the patient's death, in any proceeding in which any party relies upon the condition as an element of his claim or defense."

Task Force Report 9

Branch. The section protecting confidentiality in the act creating the Office of Drug Abuse Control specifies very clearly the conditions that a judge must consider before ordering the disclosure of confidential information. This resulted through effort via the APA.

To fully protect the confidentiality of our patients' communications, we must clearly separate the concepts of "privilege" and "confidentiality." The former term is purely legal indicating a right granted by law not to give information in a legal proceeding to influence the eventual outcome. It can be claimed only by designated parties and can be lost via various acts on the part of the owners of the privilege. In addition, information can be forced to be disclosed, and can be removed later by judicial determination that it should not have been disclosed, thereby preserving the legal purpose of privilege. This is one example where privilege is preserved but confidentiality is lost. The only safeguard to confidentiality is to legally protect the information from any disclosure.

It is in this area that the subpoena process often skirts the legal protection of the patients' privacy and the confidentiality of the information disclosed in therapy or fact of being treated or of diagnosis having been made. This requires that the psychiatrist, while honoring the subpoena, not divulge any information without the consent of the patient (COURT DEMAND PRINCIPLE I), or until the demand via subpoena has been legally evaluated and properly challenged, according to the laws of the jurisdiction in which a subpoena has been issued (COURT DEMAND PRINCIPLE II). In California and some other states, he has a legal obligation to challenge this demand. In other jurisdictions, including some Federal ones, where this legal obligation may not exist, he has an ethical obligation to do so and not release this information until all resources have been explored.

The characteristic deficiency and threat to confidentiality are inherent in the exceptions to privilege via the patient-litigant automatic waiver of the privilege protection, no matter how well protected by the limitations pronounced by the California Supreme Court as evident in actual proceedings that have followed that decision. It exists still in California law and in the current status of the proposed Federal Code, and certainly exists in the courtroom itself where these laws are interpreted. This requires that efforts be made to influence legislatures and Congress to limit the exceptions to psychotherapist-patient privilege based on experiences in the courtroom of the various states. If the language of the patient litigant exception cannot be removed entirely, it would be well to substitute the language of Section 408, Public Law 92-255: "In assessing good cause, the court shall weigh the public interest and the need for disclosure against the injury to the patient, to the physician-patient relation-

CONFIDENTIALITY AND THIRD PARTIES

ship, and (to the treatment services)" substituting for the last phrase "society's right to protect treatment." Until then, the issue needs to be challenged in the courts until precedent for adequate protection evolves. (See Appendix G.)

7. Employers

In certain occupations where the emotional health is vital to carrying out grave responsibilities, there is an obligation on the therapist to determine when and where breaches of confidentiality must be considered. It is our opinion that the judgment of danger should rest primarily on the observable job behavior and not on the mere fact that an employee is or has been in treatment. It is to the employer's benefit to encourage employees to seek early help for emotional problems. Any hazard to continued employment merely by disclosure of being in treatment will discourage such employees from seeking the help that they need to carry out those grave responsibilities safely. The applicability of GENERAL PRINCIPLE V on breaking confidentiality could apply if all the conditions are met and a clear hazard to others cannot be handled therapeutically.

In summation, the decision of whether or not to release information, while governed by the principles following, should be decided upon each individual patient and on each individual situation at the time the need for the release of this information is being considered.

Principles Governing Protecting Confidentiality in Disclosures to Third Parties

General Principle 1. Consensus is that psychotherapy requires a position atmosphere of confidentiality to protect patients' rights to the pursuit of health and happiness.

General Principle 2. We are the chief advocates for protecting our patients' right to confidentiality.

General Principle 3. Psychiatrists must never knowingly become a party to any manipulation of facts (as differentiated from withholding information dictated because of confidentiality) in dealing with third parties.

A. Unethical.

B. Just as destructive to psychotherapist-patient relationship as breach in confidentiality.

General Principle 4. Whatever is released to any third party needs to be discussed with the patient except in unusual circumstances.

General Principle 5. When in the psychiatrist's judgment the patient represents an extreme danger to himself or others that cannot be

Task Force Report 9

contained therapeutically, and it is necessary to notify others of the hazard for the protection of the patient or these others, confidentiality should be broken only to the extent necessary.



Specific considerations are mandated for certain required release of information. Absolute privacy is a thing of the past. The problem is to minimize the effect of disclosure on the patient. Requests for information from family members is one of the most frequent impositions on confidentiality. In some situations, it may help therapy.

Family Principle 1. The therapist must decide whether disclosure operates for patient or against patient. This applies to information to schools during therapy of children.

Family Principle 2. Where family is involved, there should be prior agreement on standards of confidentiality that will be applied.

Corollary — Even when total withholding of information is practiced, the involvement of family should not be ignored and they should be helped to whatever support they might need.



Requests for information from insurance companies and/or employers for treatment cost reimbursement has become the most frequent imposition on confidentiality, with proportionately grave interference with patients' welfare.

Insurance Principle 1. Patients receiving care through any system of providing such care should have access to all medical services without jeopardizing their privacy or confidential relationship with their physician.

Insurance Principle 2. The purpose of insurance is to minimize the risk and impact of calamity by spreading the risk.

- A. The patient stricken by illness in any form should not be penalized because he has added a "burden" to the group load.
- B. The patient as an *individual* should have confidentiality protected by considering group experience in all cost accounting procedures for whatever purpose.

Insurance Principle 3. Treating psychiatrists will have to give some information if their patients are to have the benefit of insurance coverage.

CONFIDENTIALITY AND THIRD PARTIES

- A. That a psychiatric condition, unspecified, exists.
- B. That symptoms began at an approximate date.
- C. General degree of unspecified impairment.
- D. General nature and frequency of treatment for billing.

Insurance Principle 4. Under no circumstances should any sensitive information from treating physician, required for insurance purposes about an individual, be routed through or be made available to employer.

Corollary — Once it has served legitimate purposes through medical evaluation, no further use should be made in identifiable individual recording or data storing.



This will be even complicated with advent of national health care coverage. There will be storage of much individual intimate material. Who controls access to information is then vital.

National Health Plans Principle 1. We must separate minimalized data needed to assure individuals' rights to care from the data needed for any statistical purpose of administration or research.

National Health Plans Principle 2. The data to be recorded for all purposes, the protection of the data once recorded, and the limitations of its accessibility should be an immediate and integral part of the initial plan.



The courts' demands for information is a less frequent occurrence, but when it occurs can have a more devastating affect on the patient and his psychotherapy.

Recent developments have been favorable.

1. California Supreme Court limiting disclosure to bare minimum when exceptions to psychotherapist-patient privilege exist.
2. Proposed federal code adopts limited psychotherapist-patient privilege.
3. Illinois further limits the exceptions to privilege.

Still needed:

Elimination of patient-litigant exception to privilege where it exists, and legislation to grant psychotherapist-patient privilege in those states where it currently does not exist.

Task Force Report 9

Court Demand Principle 1. The psychiatrist, while honoring subpoenas, should refuse, within the framework of the law, to divulge any information about a patient without the consent of the patient.

Court Demand Principle 2. If the situation involves a legal waiver of the need for the patient's consent, the psychiatrist still has the obligation to discuss the matter fully with the patient and the patient's attorney in order to be certain that all concerned understand the possible consequences of the release of information.

Corollary — The law in this area varies and sometimes a psychiatrist may be ordered to testify when he believes he should not. In those circumstances, he will have to judge whether he will legally challenge the court order and risk a contempt citation. He would be well advised to secure legal counsel first.



Employers

On jobs where emotional health is vital to carrying out grave responsibilities, the judgment of danger should rest primarily on observable job behavior and not on the fact that an employee is or has been in treatment. It is to employer's benefit to encourage such employees to seek early help for emotional problems. Any hazard to continued employment by disclosure from therapist will discourage seeking such help. (See General Principle 5)



Schools and Psychotherapy of Children

Principles relating to families apply here. A special problem is tendency of schools to develop permanent records that can be used on behalf of the child still in school, but which are available for misuse after the child leaves school.

We believe the Commission on Children and Adolescents should explore this problem for recommendations (See List of Recommendations).

Appendix G: Testimony Submitted on Behalf of the American Psychiatric Association & The American Academy of Psychiatry and the Law on the Inclusion of a Strengthened Rule 504 (Psychotherapist-Patient Privilege) in the Federal Code of Evidence H.R. 5463

CONFIDENTIALITY AND THIRD PARTIES

Maurice Grossman, M.D.
Chairman, Task Force on Confidentiality
as it Relates to Third Parties
American Psychiatric Association
&
Clinical Professor of Psychiatry
Stanford University School of Medicine
Stanford, California

Stanley L. Portnow, M.D.
American Academy of Psychiatry and the Law
&
Assistant Professor of Clinical Psychiatry
New York University School of Medicine
New York City

Presented June 5, 1974 Before the U.S. Senate Judiciary Committee

Mr. Chairman and distinguished members of this committee, I am honored and privileged to appear before you in behalf of the American Psychiatric Association, which represents 21,000 of the 25,000 psychiatrists in the United States, and also for the American Academy of Psychiatry and the Law. With me is Stanley L. Portnow, M.D., Chairman of the Committee on Psychiatry and the Law of the American Psychiatric Association, and also appearing in behalf of the American Academy of Psychiatry and the Law.

Mr. Chairman, in addition to my statement, I request to have included in the record the references and attachments appended thereto.

In proposing a strengthened psychotherapist-patient privilege rule, I find myself quite uncomfortable. In the current climate invoking privilege is a most delicate subject. Secondly, my discussion may sound critical of a fellow profession, our legal colleagues. The laws on privilege are written by lawyers, for practice by lawyers, and passed upon by lawyers sitting as justices. To the latter problem I can only claim that some of my best friends are lawyers, — not being entirely facetious since they helped me to the legal insights I will call upon. If these insights are faulty, it will be because of my difficulties and not their efforts to enlighten me. Addressing the first problem, the approach to the privilege I advocate bears no resemblance to the current legal contest. I plead for privilege, but not for protecting myself, nor for psychiatrists as a group, nor for the medical profession. I plead for the protection of our patients. It would be far easier for any physician to hide behind the legality of a court subpoena, and simply turn over his records or freely testify. It is more arduous and

Task Force Report 9

onerous to fight against subpoenas to uphold the greater ethic of protecting our patients who have placed their trust in us. A psychiatrist has gone to jail, and others have risked jail to so protect their patients. Psychiatrists and other physicians have spent tens of thousands of dollars of their own money, — not to protect themselves, — to avoid harm befalling their patients in this struggle to seek protection of confidential communications.

In essence I am really calling on you to act as a jury to pass upon the question of whether the health, welfare, and very lives of our people are being adequately protected, — the theme of our Constitution's Bill of Rights. The furor over one psychiatrist's office being invaded to get the records of one patient pales in the face of the fact that you will pass on the power to unlock every physician's file and mind about every patient's innermost fantasies, dreams, secrets and sorrows, and make them available to any lawyer, or prosecuting attorney for whatever righteous or unrighteous reason he may have. Rule 501 offers no protection because state laws are so full of loopholes they have been shown to be ineffective in actual practice (1). Approximately seven states have enacted psychotherapist-patient privilege laws (2), and these limit them to psychiatrists and psychologists; whereas proposed rule 504 included all physicians. Even so, at least in California, the patient-litigant exception has been used repeatedly to act as a barn door wide opening to attack the protection of the whole record (3) in spite of a California Supreme Court ruling (4) that disclosure must be limited and discreet.

I will not repeat endless evidence that effective psychiatric treatment rests on the patient's ability to unburden every thought, fantasy, feeling, wish to his therapist without restraint. This was documented by the Group of the Advancement for Psychiatry (5), acknowledged and accepted by the California Supreme Court in its *Lifschutz* decision (4), in the footnotes supporting Rule 504(1) as eventually proposed. There has been no argument refuting that this Rule 504 amply meets Wigmore's four criteria to support a privilege not to disclose confidential information (6).

Patients are not required to relate merely every fact, but every fleeting fantasy, wish, dream without restraint. This knowledge has often delayed people seeking help for years until the pressure of their misery drives them to chance trusting their physicians. They have already suffered hurt and distrust so trusting their psychotherapist does not come easy. The preservation of the environment of trust that no revelation will be revealed to another is what makes the practice of psychiatry possible, — and I am convinced, all of medicine. From my years of general practice I became convinced, as are many physicians, that the trust our patients put in us contributes

CONFIDENTIALITY AND THIRD PARTIES

as much to the healing process as the chemicals we call drugs, or the surgical and other physical procedures, as effective as these physical agents have proven to be. Confidentiality is essential to the proper and adequate health care of all the people.

If you reflect also on the nature of the communications, it involves not only the patients, but what they tell of their wives and husbands, their children and parents, their friends and enemies, their bosses and fellow workers. Much is fantasy and distortion, created by the fickle human mind. How many would want to be judged on the basis of every fleeting thought, wish, emotional impulse that occurs to them? Who would dare to have them exposed publicly? Yet this is the stuff of which psychotherapy communications consist. In treatment, the patient is urged actively not to censor, not to control, not to hold back such thoughts that you and I, if fortunate, hold back, laugh off, ignore, and never relate to anyone. The mere fact that they were driven to seek help only emphasizes how disturbing these have been. Patients have been driven to suicide because of inability to tolerate them. To contemplate open disclosure has driven people to suicide overwhelmed by real or imagined shame. To avoid disclosure many have suffered conditions and diseases that led ultimately to the destruction of their health and life. Many have eventually suffered destruction of careers, homes, and future. Actual disclosure has done the same.

To add the threat that a legal demand can force such disclosures from a physician trusted not to do so, bound by ethics not to do so and not to harm his patients, compounds the problem for those who seek help. To relate cases where husbands have used such disclosed information to attack their wives, — or wives to attack husbands; where disclosure about parents have shattered the lives of children; or the effect on two lives by disclosure what one individual fantasied about someone close to him only begins to tell the story (3). A psychiatrist being forced to give a diagnosis or evaluation he has made of a patient, withheld from the patient because of the patient's emotional fragility to tolerate it at the time or to understand the significance of the information, is not only destructive to that therapeutic relationship but makes it impossible for that patient and many others to ever trust any other therapist. I have seen patients precipitated back into a psychosis that years of work had overcome. So much for the need for protection and the nature of the treatment process.

What follows are some thoughts that you can best judge for validity. The problem is weighing the value of society's need to preserve that confidentiality versus what I believe is the legal right to discovery, — the search for the truth. I am not a legal scholar but my search has led to some reading. I understand the origins of the sub-

Task Force Report 9

poena, that stands for the compulsion to disclose, had its origin in the English Court of Chancery and rested on the King's right to demand disclosure (7). It isn't by chance that it became known as the Star Chamber; and Star Chamber proceeding developed a meaning well deserved (7). However, my readings indicate that the demand for the truth can be traced back through the English system to ecclesiastical courts where exacting the truth by torture, ordeals of fire and morsel, and combat were considered worthwhile in placing "need for truth" as supreme.

There are two parallels. The use of the subpoena to intimidate, frighten and hurt goes on. The niceties of Constitutional protection rigidly followed on the Washington scene are not adhered to so well in the average case. Even worse is the question whether the disclosures made during psychiatric treatment can be treated as fact, when fantasy and unconscious distortion play such a prominent role. I would ask you to give consideration to the nature of the evidence so produced, and how prejudicial it becomes. In fact by the introduction of such productions the chances are the proceedings are led away from the truth rather than to the truth.

The next question that bothers me is how the Constitution is interpreted. Article VI states "This Constitution . . . shall be the supreme law of the land". As I have been given to understand, court procedures including the rights of discovery stem from old English law. The Constitution was written to protect the people from abuses of government as found in that English law based on the Royal prerogative. Again Amendment IX states without equivocation, "The enumeration in the Constitution of certain rights shall not be construed to deny or disparage others retained by the people." Since the Declaration of Independence, that twin foundation of our Republic states that life, liberty, and the pursuit of happiness are such inalienable rights, and it seems appropriate that the Ninth Amendment makes these rights supreme in addition to the protection of the First, and Fourth Amendments. I believe I have emphasized and could further document that to withhold psychotherapist-patient privilege and physician-patient privilege violates just those rights to life, liberty and the pursuit of happiness, — especially so for the patients in the chambers of the psychiatrist, but not restricted to that branch of the medical profession.

My initial reference to the legal profession has to do with my perplexity in coping with legal logic. I understand that legal scholars have their own problems in resolving such dilemmas. Every argument I have read supporting lawyer-client privilege, if removed from the title identifying what is being defended, could apply verbatim to psychotherapist-patient privilege with even greater validity (8). I

CONFIDENTIALITY AND THIRD PARTIES

understand the American Bar Association has been critical of Rule 504. I have not heard they have come out against lawyer-client privilege. Rule 501 would establish lawyer-client privilege nation-wide via all state statutes. The Supreme Court has held that the lawyer's records are his work products and therefore are not subject to subpoena for evidence about his client (9). The courts do not do the same for the psychiatrist's records in spite of two factors more pertinent than those that apply to lawyers. The psychiatrist records his spontaneous impressions of what he thinks the patient is really expressing and thinking, which is not exactly what the patient's words were (so called "interpretation of the contents"), — therefore a product of the psychiatrist's mind. Secondly, many psychiatrists keep no records at all of the patient's communications, demonstrating that the records are not for the benefit of the treatment or the patient, but for the study of the psychiatrist's own functioning and interpretations for ultimate verification. Thereby that patient and all subsequent patients benefit. To force all psychiatrists to give up record keeping would be a disservice to the research, teaching and improvement in the practice of psychiatry.

I would request the Committee to ask themselves what factors might influence the weighing of the two constitutional values involved. This request might also be considered by the American Bar Association. Originally the Federal Procedural Code insisted that a subpoena could be issued only by "showing good cause" (10). Court interpretations established that this required more than mere relevance to the issue; and required that there must be evidence the information was vital to the preparation of the case (11). In 1970 this Fourth Amendment protection was dropped. The Advisory Committee on Rules, after giving legal justification added, "(because) it reflects existing law office protocol" (12). I am sure this Committee and the Congress as a whole would not subordinate the First, Fourth, and Ninth Amendments of the Constitution to the convenience of the law office; to ease the efforts of practicing lawyers, let alone the support of interested groups who profit from using the threat of disclosure.

I am requesting you put a firm lock on the offices and minds of all physicians so that predators cannot invade the rights protected by the First, Fourth and Ninth Amendments through the legal permission of those trying to support justice in the courts. It is important to weigh whether the remedy for justice in seeking the truth does not create greater injustice reaching out to multitudes not even directly involved in the specific court action.

I would further implore that you strengthen the lock that is Rule 504 in two ways. This need is suggested by actual experience in the

Task Force Report 9

California courts. Illinois recognized this when their legislature almost eliminated entirely the patient-litigant exception (section (d) (3) in 504). They finally compromised for divorce and child custody cases (13). The California Supreme Court tried to correct this in its *Lifshutz* decision, but lower courts have been unable to apply the rule suggested. A substitute for Rule 504 (d) (3), patterned after Section 408 (b) (2) (C) of P.L. 92-255 might be more helpful to the courts (14). This section 408 has held up well in courts. Otherwise the ills already demonstrated by the operation of a blanket waiver will continue to plague the courts. It places the patient wise enough to seek help in a position unfavorable to those who needed but avoided such help (15). The rights to the courts should not be conditional. It results in unequal application of the law. It has deterred people from seeking help as they pursue just claims. Evidence can and has been secured from sources other than the treating psychiatrist, but this has not stopped the inroads of confidentiality of the treatment relationship even in those states having protective privilege laws.

The argument presented that it permits scoundrels to hide behind the protection of the law (16) is a specious one. There are such cases. First, are the many to be harmed because of the few who may so try? Secondly, in each such case, there was a lawyer who took and filed the action before the physician was brought in. I leave the inference to you to avoid sticking my neck out any further.

To strengthen the lock even more, the original proposal for Rule 504 extended the protection to all physicians. In the few states having any protection it is limited to psychiatric physicians. The 504 wording in Section (a) "while engaged in the diagnosis or treatment of a mental or emotional condition" overlooks the frequent phenomenon that disclosure of a communication or finding of a condition might precipitate a mental or severe emotional condition, — sometimes if only revealed to the patient (e.g. labels of syphilis, gonorrhea, pregnancy, schizophrenia, latent homosexuality). I would suggest a modification of the wording to foresee these possibilities (17).

The question of extending the right to claim the privilege to the therapist is a moot point (see addendum). The protection is always of the patient and the patient's right. Extending to the therapist the right to claim the privilege seems indicated when the patient is incompetent to understand the consequences (e.g. mentally incompetent; having no knowledge of what he has actually communicated or therapist's observations and judgments withheld from patient because of patient's condition). Here we have a situation lacking informed consent. The other situation is where the patient's attorney is more concerned with a settlement (usually in contingency cases) than he is in what happens to his client. This latter is a question for the legal

CONFIDENTIALITY AND THIRD PARTIES

profession to determine whether they want a physician to protect the client from his own lawyer. These situations do exist.

In summary I ask that you review the nature of the psychotherapeutic process; its dependence on trust that requires confidentiality; the nature of the evidence that would be labelled, used and misused as "fact" or "truth"; the availability of other sources of information. I also ask that you consider the effect of threatened exposure on those needing, seeking, or already in the process of treatment; in that light to recognize Wigmore's four postulates for privilege have been met even better for Rule 504 than for lawyer-client privilege. I would ask that you review the history of "ascertaining the truth in the courtroom" in juxtaposition to the protection sought by the framers of our Declaration of Independence and the Constitution. As a result I do hope you will restore a stronger lock for the protections in those documents by restoring a strengthened psychotherapist-patient privilege in the Federal Code of Evidence. I can do no better than to quote from David W. Louisell's review of opinions ". . . that whatever handicap privilege places upon adjudicatory process is not too high a price to pay for preserving inviolate certain essential relationships." (18) Preserving life, health and the pursuit of happiness should stand high in priority for such consideration.

Mr. Chairman, I also wish to emphasize to this committee that the inclusion of the psychotherapist-patient privilege can be inserted in addition to the traditional physician-patient privilege which must not be impaired in any way.

REFERENCES

1. Committee on Rules of Practice and Procedures, Judicial Conference of the U.S., *Preliminary Draft of Proposed Rules of Evidence for the U.S. District Courts and Magistrates*, footnotes Rule 504 (1969, p. 53).
2. California, Connecticut, Florida, Georgia, Illinois, Kentucky, Massachusetts.
3. Slawson, P.F., "Patient-Litigant Exception," *Arch. Gen'l Psychiatry* 21:347; Sept. '69 — Slovenko, Ralph, "Psychiatry and a Second Look at the Medical Privilege," 6 *Wayne L. Rev.* 175-188 (1960) — Robertson and Caesar cases that reached California Supreme Courts; references are not available but can be secured if needed.
4. *re Lifschutz* 2 Cal. 3d. 415, 467 P. 2d 557, 85 Cal. Rptr. 829 (1970); *Roberts v. Sup. Ct.* 9 C 3d. 337 (Calif. Sup. Ct. 4/11/73) — Louisell, David W. & Sinclair, Kent, Jr., "The Supreme Court of California," 1969-70," 59 *Calif. L. Rev.* 30, Jan. 1971.
5. "Confidentiality and Privileged Communication in the Practice of Psychiatry" Report No. 45, Group for the Advancement of Psychiatry, New York, 1960.

Task Force Report 9

6. 8 Wigmore Evidence, Section 2285, p. 527 (McNaughten rev. 1961)
 - (1) Originates in confidence it will not be disclosed.
 - (2) Confidentiality essential to the relationship.
 - (3) The relationship should be fostered for the welfare of society.
 - (4) The injury to the relationship greater than benefit gained to litigation by the disclosure.
7. Plunknett, Theodore F.T., *A Concise History of the Common Law* 4th ed. 1948 p. 172. — Webster's New International Dictionary of English Language unabridged, 2nd ed. 1960, p. 2458, G.&C. Merriam Co., Springfield, Mass. — Oxford English Dictionary, V.9, Pt.1, 1919, p. 833 ed. by Henry Bradley.
8. Compare:

Slawson, *supra* 3, p. 352, quoting Lord Justice Knight Bruce. Doyle, Vincent, "The Privacy of the Individual," *World Med. J.* 21:p. 33 March April 1974, same quote.
9. Hickman v. Taylor, Jan. 1947, 329 U.S. 495, 67 S. Ct. 385 "Not even the most liberal of discovery theories can justify unwarranted inquiries into the files and mental impressions of an attorney."
10. Federal Rules Civil Procedures, Rule 34 28 USCA.
11. *Fastener Corp. v. Spotnails, Inc.* D.C. Ill. 1967, 43 F.R.D. 204 U.S. v. *Am. Optical Co.* D.C. Cal. 1966, 39 F.R.D. 580.
12. See Ref. 10 *supra* notes to amendment March 30, 1970 Advisory Committee on Rules — "The revision of Rule 34 to operate extrajudicially rather than by court order reflects existing law office protocol" (emphasis added).
13. State of Illinois Statutes, Chapter 51, Evidence & Depositions, Section 5.2 (c) as amended 1971 — Beigler, Jerome S., "The 1971 Amendment of the Illinois Statute on Confidentiality: A New Development in Privilege Law," *Am. J. Psychia.* 129:3, p. 311, Sept. 1972.
14. *In re Lifschutz* *supra* 4, footnote 26.

Suggestion for wording 504 (d) (3) — "When patient injects the issue of his mental or emotional state as a claim or defense the privilege will be waived only if a court of competent jurisdiction considers there is insufficient necessary evidence from sources other than the psychotherapist. In assessing such good cause the court shall weigh the public interest in protecting such communications, and the need for disclosure against the injury to the patient, to the psychotherapist-patient relationship and the effect on the treatment process. Even so, disclosure must be directed at specific questions that need answers."
15. *Roberts v. Sup. Ct.* *supra* 4.

Grossman, Maurice "Proposed Federal Code of Evidence Rule 504 — Psychotherapist-Patient Privilege" Feb. 23, 1973, unpublished copy attached.
16. Wigmore, *supra* 6, Section 2220, p. 183.

CONFIDENTIALITY AND THIRD PARTIES

17. Suggested wording — "... while engaged in the diagnosis or treatment of a mental or emotional condition, or receiving information that might precipitate a mental or severe emotional condition."
18. Louisell, etc. *supra* 5, p. 53.

ADDENDUM TO TESTIMONY

Case for the Psychotherapist Exercising the Right to the Privilege in Order to Protect the Patient
Maurice Grossman, M.D.

I would prefer to view the therapist exercising the right of privilege from another viewpoint, which was alluded to in Lifschutz's pleading, but received inadequate consideration in the Court's discussion of its decision. It would be based not on his rights, but on his obligation. Apart from his obligation to maintain a "safe atmosphere" for all prospective patients, he has an obligation to protect the individual patient even from the patient himself. The extreme case obviously is in the act of attempting suicide. But the same factors operate in other less manifest ways. This leads to my second approach to the problem.

The legal process sees every individual as competent to make decisions and therefore responsible for those decisions. Obviously, our society could not operate on any other basis. Yet the law recognizes that this is not so in certain circumstances. The gross circumstance of legal insanity and the resultant various complications of legal competence is the most obvious. The guiding principle rests on the relevance of the mental state to the act in question. *The individual's mental ability to adequately judge and control his act is the guiding principle.* In psychotherapy the patient is encouraged to drop all intellectual controls and to say anything that comes to his mind without censoring by reason or fact. In the process he drops all "adult," "mature" controls and regresses to earlier childhood and even infantile states of thought production and their verbalization. He might then release immature, even irrational emotional urges, impulses and thoughts. More important, he might, and often does, associate these infantile resurgences to present day activities in his verbal productions in the therapeutic session. The examination of these irrational impulses in the light of rationality, with the therapist's help, is the important instrument in therapy. Sometimes there is a tendency for the patient to "act out" these irrational impulses in everyday life. There is a cardinal rule for patients to avoid committing themselves to any irreversible act while in therapy until the irrational elements are understood. The reason for this is that all patients in intensive therapy, and to some degree all patients in any

Task Force Report 9

psychotherapy, regress to these earlier states of feeling, thinking, and even functioning. In the course of this they sometimes act as various members of their childhood family, as they saw themselves then, or as they fantasied themselves in wishful thinking.

In other words, encouraged to drop controls they regress to where these productions are neither wholly factual or within their reasoning control. The psychological processes of repression and defensive distortion are accentuated during therapy, and only the therapist stands as their protector against their irrational self. The patient endows him with the cloak of a benevolent, non-punitive, protecting parent. It is this role that permits him to be effective. It is this role he must not jeopardize.

The law recognizes that at certain ages children are incapable of being held responsible. Many of the assertions of patients are from the childhood points of view. To take their utterances during a psychotherapeutic session as responsible fact would ignore the reality of the therapeutic scene.

The mere fact that they sought treatment is evidence enough that their conscious behavior and reactions were having irrational consequences. It is this more or less unconscious awareness of the irrationality of some segment of their being that makes patients reluctant to even disclose they seek the help of a psychiatrist.

I would then suggest that consideration be given to the psychotherapeutically induced intrapsychic state of the patient at the time he makes statements to a therapist; that it be viewed in the light of regressed distortion; and that it is a mixture of fact, fantasy and distortion that should not be acceptable as "evidence of fact." On this basis, in court, the therapist is in a position where he must protect the patient from having the proceedings of the therapeutic process taken at face value. The patient may not even know what he is actually saying or intending to do. Not infrequently in practice, patients are amazed at recorded statements and cannot explain how they came to say them. The therapist uses them as guideposts to the unconscious. To treat them as a "fact" in court would be a perversion of justice. At times patients will demand the therapist support lines of action that the patient is convinced is essential for his well-being. When the patient proceeds even after the therapist points out the irrational driving force, he might still attack the therapist for not having stopped him, if the act backfires.

The summation of the above is to support the proposition that the therapist needs the right of privilege to permit him to adequately exercise his responsibility as the protector of his patient, even from the patient himself. He must always refuse to testify on broad principle to make sure refusal in specific cases is not taken as an admis-

CONFIDENTIALITY AND THIRD PARTIES

sion of some secret forbidding trait in a specific patient.

The question of informed consent as applied to waivers of privilege by patients in therapy is an entirely different aspect. The above discussion would be relevant to that. The reliance on the patient's waiver might well be questioned in this approach.

Some clinical examples are:

1. Patient reacts to current situation that evokes unconscious memory of childhood trauma and anger. Statements in therapy taken out of context of the therapeutic scene, would be a gross distortion of actual behavior on job. Yet he feels tremendous guilt about job performance based on his childhood guilt. His statements, in court, could be used by adversary as though they were facts, confusing a jury.
2. Those patients, because of neurotic needs, repeatedly feel they are committing grave crimes. The extreme are innocent individuals who come to confess they might be the culprit in publicized crimes. Lesser versions of these are apparent in other self-blame statements during therapy, especially when pushed into taking aggressive action like filing a lawsuit. *And these are not psychotic individuals.*
3. Freud's famous experience of adult patients reporting they had been raped at time of puberty; and his eventual realization they were reporting fantasies as though they had been real.
4. Those patients signing for release of information by therapist under social pressure (boss on job, husband of wife-patient); or the passive submissive patient who literally cannot refuse; and both groups depending on the therapist stepping in to say "No."
5. The insurance company refusing to pay for covered treatment, asking more and more details of the case. To file suit, the patient jeopardizes his privacy. In two instances, both non-psychiatric, the claimant dropped the issue without recovering his payments, out of fear of upsetting his employer who had the insurance contract.
6. Slawson's case is still relevant, even though divorce proceedings have changed. A patient's inability to collect insurance because to report desired information, would be through husband, the insured one, and might be used by him in child custody proceedings. In the one I know, the fear of it being used was based on unconscious dread, rather than any real danger; but the effect was equally as destructive at that stage of treatment.

Task Force Report 9

7. The hypothetical school teacher suing for his job. The school administrators use knowledge of the teacher using group insurance for psychotherapy, demand the record to support their contention of unfitness, rather than testimony of actual job performance deficiencies. I would guess that the average judge would admit the whole record. There have been reported instances of misuse of psychological tests in basing action on such words as "latent homosexuality," "high on femininity scale" for men, "aggressive tendencies," etc. In court, any expert evidence that the terms have no relevance separated from any overt behavior, would not reduce the impact of such terms on a jury.

ADDENDUM TO TESTIMONY

Pub. Law 92-255, March 21, 1972

#408. Confidentiality of patient records.

- (a) Records of the identity, diagnosis, prognosis, or treatment of any patient which are maintained in connection with the performance of any drug abuse prevention function authorized or assisted under any provision of this Act or any Act amended by this Act shall be confidential and may be disclosed only for the purposes and under the circumstances expressly authorized under subsection (b) of this section.
- (b) (1) If the patient, with respect to whom any given record referred to in subsection (a) of this section is maintained, gives his written consent, the content of such record may be disclosed.
 - (A) to medical personnel for the purpose of obtaining benefits to which the patient is entitled.
- (2) If the patient, with respect to whom any given record referred to in subsection (a) of this section is maintained, does not give his written consent, the content of such record may be disclosed as follows:
 - (A) To medical personnel to the extent necessary to meet a bona fide medical emergency.
 - (B) To qualified personnel for the purpose of conducting scientific research, management or financial audits, or program evaluation, but such personnel may not identify, directly or indirectly, any individual patient in any report of such research, audit, or evaluation, or otherwise disclose patient identities in any manner.
 - (C) If authorized by an appropriate order of a court of competent jurisdiction granted after application showing good cause therefor. *In assessing good cause the court shall weigh the public interest and the need for disclosure against*

CONFIDENTIALITY AND THIRD PARTIES

the injury to the patient, to the physician-patient relationship, and to the treatment services. (emphasis added) Upon the granting of such order, the court, in determining the extent to which any disclosure of all or any part of any record is necessary, shall impose appropriate safeguards against unauthorized disclosure.

- (c) Except as authorized by a court order granted under the subsection (b) (2) (C) of this section, no record referred to in subsection (a) may be used to initiate or substantiate any criminal charges against a patient or to conduct any investigation of a patient.
- (d) The prohibitions of this section continue to apply to records concerning any individual who has been a patient, irrespective of whether or when he ceases to be a patient.
- (e) Except as authorized under subsection (b) of this section, any person who discloses the contents of any record referred to in subsection (a) shall be fined not more than \$500 in the case of a first offense, and not more than \$5,000 in the case of each subsequent offense.

ADDENDUM TO TESTIMONY

PROPOSED FEDERAL CODE OF EVIDENCE

RULE 504 — PSYCHOTHERAPIST-PATIENT PRIVILEGE

This rule for privilege in psychotherapy recognizes Constitutional ground for such protection.* Not to grant such privilege would interfere with the rights of an individual to seek health and protect life because it is recognized that patients requiring psychiatric care would be reluctant to seek such care unless they were assured that disclosure of embarrassing or damaging material would not get beyond the physician they are consulting. Furthermore, for psychotherapy to be effective, it requires that patients hold back no material and disclose everything and anything that is involved in their emotional processes. Here again, this would not be possible unless the patients really were assured that there would be no release of such information beyond the therapist. This was recognized in the deliberations of the California Supreme Court in the *Lifschutz* case.

Based on these same principles, a similar law was first passed in Connecticut and was considered by all concerned, both in the legal and psychiatric professions, that it offered adequate protection to patients and the law. A similar law was adopted in California and is now part of the California Code.** A similar law was passed in Illi-

*California Supreme Court decision in *Lifschutz*. 2 Cal. 3d, 431-32, 437, 467, P. 2d at 567-68, 571-72, 85 Cal. Rptr at 839-40, 844.

**1970 Revision Article 7, Sections 1010-1028.

Task Force Report 9

nois, and in 1971, amendments were necessary based on problems created by the law, based on the exceptions to the privilege that were incorporated as part of the basic law. These same problems have developed in the application of the Code in California. The source of the problems are the exceptions, based on the patient's mental or emotional condition being entered by the patient as an element of a claim or defense (California Section 1016; Federal Code Rule 504 (d)(3)).

The legal philosophy for this exception is that if patients use their psychiatric condition for a claim or defense, the truth concerning this requires access to all the material bearing on this; and that patients need not make the claim and can so preserve their confidential disclosures. In practice, it turns out that, because of this, patients are given the choice of pursuing just claims under conditions of costly emotional damage; or to forgo just claims, — conditions not suffered by claimants not in treatment.

Furthermore, this concept treats the disclosure of patients during treatment as facts that are of reliable truth. The actual nature of the revelations of patients in therapy are far from fitting these criteria. The patients' emotional involvement in the material of disclosure results in distortions and often outright untruth, unconsciously produced, that are part of their neurotic or psychotic process. This is compounded by the nature of the therapeutic process that encourages patients to regress to childhood states during therapy in order to reach hidden childhood factors involved in their psychiatric problems. This forces the patient to drop all adult reality controls that keep healthy adults' thoughts and utterances in truthful perspective.

The California Supreme Court in the *Lifschutz* case recognized some of these factors, with particular reference to the extreme damage that could be done to such patients if their therapists were to disclose material given in such confidence. They tried to bridge the two factors involved, — that is, the patient's need for protection and treatment and the court's need for information, — by determining that disclosure should be restricted and limited to that information relevant to the proceedings. This decision seemed to resolve the problem, except that in practice in courtroom proceedings almost immediately following this decision of the California Supreme Court defendants (their insurance company attorneys) have insisted on free right to full disclosure, even in depositions, forcing psychiatrists to protect their patients at considerable hardship to themselves (*Lifschutz* going to jail, he and at least two others being forced to go through appeals that were more costly in time involvement than the \$10,000 to \$25,000 legal expenses each incurred in protecting their

CONFIDENTIALITY AND THIRD PARTIES

patients).

In the case of Dr. Robertson, when the California Supreme Court accepted the appeal to review an adverse decision of the lower appellate court, the defendant settled for the original claim amount rather than risk a Supreme Court decision, suggesting the exclusionary section is used for harassment of the patient and psychiatrist.

In actual proceedings, patients claiming their psychiatric condition in issue, still have to prove relevance and truth of such claim. Expert testimony other than their psychiatrist can be subject to cross-examination; or the patient can resort to the doctrine of *res ipso loquitor*. Therefore, sources other than the therapist are available for ascertaining the truth of the issue. In Dr. Robertson's case, a non-treating psychiatrist had examined the patient, was being used for the plaintiff, and was available for cross-examination. In another case involving a Dr. Caesar, an eminent psychiatrist called by the plaintiff patient, testified that the patient's mental state was not due to the accident in question, but the defendant's attorneys still pressed disclosure from the therapist, Dr. Caesar, — again suggesting harassment as a threat to psychiatric patients who sue.

Another problem has to do with legal view and legal procedures handling such information. If such information can be elicited in deposition where there is not the protection of the court itself, even though this information may be stricken from the record based on both the law and judicial protection, the damage to the patient has already been done. We have record of cases where such depositions were read in court with damage to the patient, and even though the information was then stricken from the record for legal purposes, the psychiatric damage had already been incurred. The question of legal admissibility and reversal is an entirely different problem from protecting the patient from breaches of confidentiality of the material given in private to their treating psychiatrist.

In North Carolina and in the section protecting confidentiality in the federal law setting up the Office of Drug Abuse Control and proposed legislation for Veterans Administration drug abuse treatment programs, protection was dependent upon requiring the judge in court to make a determination whether there were overriding needs for information that warranted intrusion and destruction of the patient's need for confidentiality. In the drug abuse program, the need was not really for the protection of the patient, but the recognition that the whole program and its success was dependent on patients feeling secure that their seeking treatment and records of treatment would not result in legal and other civil problems. As noted from the attachment, it can be seen that even this failed in New York City, where the trial court judge and the Appellate Division of the

Task Force Report 9

New York State Supreme Court ruled that the photographs of all patients in the treatment program be made available to witnesses and legal authorities in a hunt for a suspected murderer. At last word, this was being requested for review by the New York State Supreme Court, with consideration of appealing to the United States Supreme Court if necessary.

Additional attention is needed to the problem of protecting patients in psychotherapy, not from the intent of the law, but from how it works out in actual practice.

Maurice Grossman, M.D.
February 23, 1973

CONFIDENTIALITY AND THIRD PARTIES

*Appendix H: Samples of Reports From Psychiatrists of Injuries
to Patients Resulting From Breaches of Confidentiality
Compiled by Maurice Grossman, M.D.
Chairman of the Task Force*

In the following illustrations, distortions have been purposefully made to disguise identification and in some instances the essential facts are gleaned from multiple cases.

1. A 24 year old schizophrenic patient, receiving EST in hospital improved and was able to return to work. Patient not told actual diagnosis because of still fragile state. Insurance covered patients routinely are given forms to sign on hospital admission. Includes permission to give information to insurance company. Hospital sent a report of the hospitalization as routine matter to get payment for bill, including diagnosis and suicide attempt. On return to work, patient found that fellow employees knew of the hospitalization, the incidents. Insurance company sends report to employer on group contract coverage. Patient becomes paranoid toward her physician; expresses self about first learning about herself from fellow employees; terminates treatment.
2. Similar case, with patient learning of diagnosis with notice from insurance company reporting they had paid the bill. Patient paranoid about how insurance company, and "their clerks" knew all about it.
3. A very emotionally upset patient, first making inquiries from insurance company that no information would reach employer, was so assured. The entire therapy damaged, and patient worse when finds employer discloses knowledge of the treatment and other factors. Medical Director of the national company involved, and a high official in insurance organizations writes "we are obligated to tell the employer because he pays the premiums." (Note that such group contracts are fringe benefits paid for by employees labor, and are only administratively paid for by employer.)
4. Patient called in for questioning about insurance report of psychiatric illness relative to security clearance even though no interference with work. Incident to security investigation, neighbors were asked what they might know about any psychiatric problem about this patient.
5. Reports of employers looking for excuses to separate employees based either on prejudice about psychiatric illness or unwarranted concern they will add burden and increased

Task Force Report 9

insurance premiums on group policy.

6. One patient, spouse of employee covered by group contract, required intensive treatment because of extreme emotional decompensation, — barely holding together and very depressed. When husband filed claim for the costs of treatment covered by policy, he was told that employer would be told of his claim; that employer would be required to increase premium payments on all employees (declared not to be a fact by insurance industry representatives when discussed with them later); and intimidated him into dropping the claim out of fear of losing job. The physician was dissuaded from making follow-up inquiries both by husband and wife out of fear of losing job. Patient became worse.
7. School systems who routinely turn down applications for teaching positions on any history of psychiatric care, derived from insurance questionnaires, without investigating the nature of the condition or treatment to determine whether it would have a deleterious effect on their teaching or contact with children. Many in treatment are better teachers than those who avoid it.
8. Many government agencies routinely request information about psychiatric treatment. If ignored, and later insurance information based on group policies discloses it, they may be separated on that ground. If they admit that they had treatment, they do not get job in first place. No effort is made to have individual examined to see how relevant the history is to present condition or job. (Incidentally I have found that the Department of Defense Industrial Security Review Agencies is the most careful to protect the confidentiality of material from employers and to evaluate current condition in relation to the job. The one difficult problem still is that of those who admit to homosexuality. I understand the Civil Service Commission has just agreed to drop this section of the questionnaire for job applicants, and rely on current examinations.)
9. Two high officials in the Department of Defense, defending the practice of SPN identification on conditions of discharge that includes medical data, unequivocally declared before a Senate Committee that they feel obligated to tell employers of the reasons for his discharge, when the discharged military person, returned to civilian life, seeks employment. (Again, I understand that recently the use of SPN identifications have been dropped; but the question of attitude remains open.)

CONFIDENTIALITY AND THIRD PARTIES

10. Records of a child's psychiatric condition and treatment made a permanent part of that child's school file when the treating psychiatrist has consultation with the current school teacher and parents, are often used in later years by others not having the benefit of the psychiatrist's help in understanding the information; nor allowing for changes as the child progresses; and has even been turned up in search for information in the adulthood of the patient long after school years.
11. Patients returned to stability and able to work, forced back into their psychotic state by misuse of material released from insurance files, security clearance files, that reaches other parts of employment situation. Undoing years of therapy is only part of the price. Suicide attempts; homicidal threats based on paranoid upheavals; all generated by real attitudes about them from fellow employees who repeat the information for either sadistic or thoughtless reasons.
12. Since spouses are often the ones covered by the group policy and many insurance reports are required to go through the plant's personnel office, even a diagnosis can cause trouble. Not infrequently there is already some trouble in the family. The "well" member is not above using the fact of treatment to blame the "patient" for all the difficulty merely because the "patient" has been the one to accept the treatment. There have been cases where the spouse has used the diagnosis to threaten the "patient" as a means of dominating the household situation, even after the "patient" has recovered and become constructively functioning.
13. A variation of this is where the insured spouse seeks divorce, and threatens or actually seeks custody of children. When the insurance report indicated merely that an emotional condition existed, but that the physician would discuss it directly with the medical director on condition that it would not be disclosed elsewhere, the insurance company refused to pay the claim. The husband kept threatening the wife, to get a report for him to turn in through employer channels. A "secret" insurance company memo about the treating physician went through channels to the employer, got to spouse, who showed it to patient, who showed it to M.D., example of how protected their records really are, even when it concerns themselves.
14. This last case represents another problem. When it was discussed with the insurance commissioner of that state, he

Task Force Report 9

replied it was an individual matter and that payment would have to be sought in the courts. However, laws on privilege would require opening up the entire record in court, so that the damage would again be done. It has been found that detailed questionnaires are designed mostly for that purpose. Even if sued, the insurance company would merely have the same amount to pay and most people fearing the disclosure merely drop their claim for reimbursement.

15. There are many patients, covered by insurance, who will not use their benefits because it will get back to employer. We receive reports that there are many more, who need care, but cannot afford it unless paid for by the insurance they have, but forego treatment rather than take a chance.
16. We have other reports from reliable sources, but which cannot be documented for obvious reasons, of people greatly in need of treatment, but because of critical nature of their employment, avoid treatment out of fear of disclosure from any source. Such groups are commercial pilots, military officers, certain professional men and women, people in high executive positions or on their way up the executive ladder. They can point to instances of those they know who chanced treatment, only to have leakage of information from some source interrupt their career.
17. These are not restricted to psychiatric cases alone. A surgeon hospitalized for a coronary attack, learned shortly after he was home that his automobile insurance had been cancelled. His broker informed him that his automobile insurance carrier had gotten word of his coronary through means of his hospital insurance report.
18. One of the patients listed above told of a claim for corrective eye surgery on a child that was refused by the insurance company although supposedly covered; and the family dropping the claim fearing repercussions from the employer. This was at a critical employment crisis in the industry.
19. A patient applied to her physician for a physical examination for life insurance. When her application was turned down, her agent obtained a full report for her, and indicated that her physician was responsible. That terminated that relationship. The physician reports he couldn't understand the rejection on his report per se.
20. At the March 1974 C.M.A. Annual Meeting, at a reference committee hearing, a physician reported a case who died, and

CONFIDENTIALITY AND THIRD PARTIES

whose life insurance payment was refused. Many years before in the course of some other illness, he noticed a benign nodule that was not treated. When the patient applied for insurance the nodule was not listed among old conditions. Since her application was less than two years before her death, payment was refused on the basis of a fraudulent application even though it had no bearing on the cause of death and was so unimportant the patient probably forgot it. The information came from one of the insurance data storage centers, or in the course of investigation, using the blanket consent form, they searched old records and found reference to it in list of diagnoses.

21. One report is of a hysterical patient with hypochondriacal symptoms who had, as a result, many bouts of surgery. After a year or so of treatment, with focusing on underlying problems, the symptoms and the surgery came to an end. When the patient began using insurance, a demand was made for an official diagnosis. The physician used "Hysterical Personality Defect". Through some way unknown to the doctor, the actual diagnosis became known to the patient. In her fury she immediately stopped treatment. The next he heard she was back visiting surgeons again.
22. A patient who had been hospitalized for severe emotional disorder had had extensive psychological testing done at the hospital. A claim for hospital payment had been sent in by the hospital. Again, as often demanded by carriers, the hospital sent along a full report. For some reason they even sent a copy of the psychological test report. (Our information did not include whether there was separate billing for the tests.) Because some questions had not been fully covered, the insurance company returned the whole application, including all the reports. For some reason, they returned it to the patient instead of to the hospital. The attending physician reported that the material was more than the patient could tolerate at that time and resulted in a relapse. He also reported that in another patient the results could have had a permanent, more drastic effect.
23. Special problems are those faced with disclosure via subpoena and court disclosure. Many cases are reported of individuals, involved in court procedures, having legitimate claims, e.g. after accidents; needing to secure compensation because of losses and medical costs; having severe emotional reactions after the event; and being told by their at-

Task Force Report 9

torney the psychiatrist could be subpoenaed to testify, refused to consult anyone for the help they needed. This has been reported both by attorneys and physicians.

24. A variation of this is the patient already in treatment who gets into court action. A number have had to forego just settlement rather than chance testimony in court about their disclosures to their psychiatrists.
25. These fears are not without foundation. In one case, a psychiatrist was forced to testify in detail about the patient's marital problems at a deposition. Being a deposition and understanding it had no relevance to the issue, but being made to testify anyhow, he went into the details when specifically questioned. He heard later from the patient that every detail was read out in open court in the presence of the spouse. The patient won the suit but had a destroyed marriage.
26. In another, the demand was to give the full record on a child. To do so would have disclosed to the child in court that his real father had committed suicide, a fact he never knew. He refused to testify. We have no information on what basis he was able to avoid doing so.
27. In another case the psychiatrist answered some questions. When he refused to answer some that he thought would do irreparable harm to the patient, he was held in contempt of court. His appeals went all the way to the State Supreme Court without relief. Appeals to the Federal Courts have as yet not brought relief.
28. In California, welfare patients are limited to two visits a month to a psychiatrist. If a case requires more treatment than that, a Treatment Authorization Request (TAR), is required giving in detail, the clinical facts to substantiate how sick the patient really is. Someone photocopied a number of these TARs to demonstrate how easily the information can be obtained. They were sent to me anonymously, so I have no way of knowing their source. The postmark was from Southern California. The typing and form was so varied, I can only assume they came from a central file. Some were of children telling of their various criminal activity. One told of the child witnessing one parent killing the other. Some contained information of sexual activity. The obvious facts are that only those who are very sick would require TARs in the first place. Secondly, in order to get the authorization, all the severe pathological details have to be included (reports indicate how

CONFIDENTIALITY AND THIRD PARTIES

in some obvious severe cases, requests are refused). The next obvious fact is that these written records are not secure. There is no evidence that these records are ever destroyed. Once California starts computerizing these records with a state wide interlocking system, access to such records can be done more easily, without leaving a trace.

In a report of the World Medical Association Congress meeting in Munich, Germany, October 1974, it was reported that such countries as Denmark and Belgium are already using all such information by all government agencies. The New York Times carried similar information from Sweden. The American Psychiatric Association, anticipating this problem, formulated a Position Paper in 1970, warning, and suggesting protective steps be written into any National Health Insurance legislation.

29. There has been a report that one state, computerizing its psychiatric records, used convicted inmates of its penitentiaries to transfer the crude, raw data to punch cards; making identifiable material available to those doing the work. The last report is that the project was finished.

June 15, 1974.

Special Note

Readers may also be interested in *Psychiatry and Confidentiality, An Annotated Bibliography*, prepared by the Library Staff of the American Psychiatric Museum Association, 1700 18th Street N.W., Washington, D.C., 20009, September, 1974. Mimeo, 51 pages, \$2.50.

Dr. BEIGLER. I thank you again for the opportunity and privilege of making this presentation before your subcommittee, and thereby being allowed to participate in our vigorous democratic process. If I can be of further service, I am pleased to remain available.

Mr. DRINAN. Thank you, Dr. Beigler, for your statement.

Dr. Beigler, what is your opinion on the consent for release of records through the insurance industry?

Dr. BEIGLER. We had to make a compromise as far as our provisions for informed consent of release of records through the insurance industry. The political balance was such there was no room for negotiations, so we had to compromise that particular issue. Hopefully, there might be Federal legislation to neutralize that problem or perhaps in the future mandatory legislation. Otherwise, we find it satisfactory with perhaps a couple technical problems on which we ourselves will hopefully initiate corrective legislation.

Mr. DRINAN. On the collaboration with the law enforcement agencies which you mentioned here, I wonder if you would comment on this. All of the bills proposed at the Federal level permit disclosure of medical information to the Secret Service. It says in the administration bill that "the Secret Service may ask the hospital or other individuals and, if the Secret Service simply states that they need this information, the disclosure is authorized."

Would you comment on that particular provision?

Dr. BEIGLER. Our Illinois law provides access by the Secret Service only as far as State hospital institutions are concerned, and then the information is limited to the specific stipulation, such as name, age, cause, duration of hospitalization, rather than disclosure of irrelevant clinical material. Those are the provisos of the Illinois law.

I am well aware of the importance of having access in these situations. We would just have to wait and see what our experience is in the State of Illinois. We would recommend that the prejudice be in the direction of Illinois law rather than indiscriminate access.

Mr. DRINAN. Would you react to what was proposed by people on the panel here before; namely, that a uniform State law be adopted by the 50 jurisdictions?

Dr. BEIGLER. I have had occasion to reflect on that problem. I have asked my legal scholar friends about this problem. They pointed out to me that, again as in most of these situations, there are two countervailing rights.

On the one hand the simplicity of having a uniform Federal legislation has certain advantages that are obvious. On the other hand they point out to me that there is such a thing as creativity that might be stifled should there be a uniform Federal law, and that leaning in the direction of asking for individual laws for each of the 50 States might stimulate the creativity of the people at this level of government.

In my own uninformed way, I do not see any reason why there cannot be a combination both of license for individual State laws and a Federal law as a guide.

During the deliberations of the new evidence code for the Federal courts, there was a proposed rule 504 that provided for psychiatrist-patient privilege. We supported that proposed rule on the basis that it would set the standard for Federal courts and that

this would infiltrate down to the various States' Federal courts, and eventually would affect the shaping of State legislation. It seemed to me that had some advantages to it. That is what I would have in mind.

As far as privilege law over the country is concerned, I believe there are only 10 or 12 States that have any privilege law or psychiatrist privilege laws. In the other States, as I understand it, almost any information can be obtained almost at will. Therefore, from that point of view a Federal standard would be helpful.

Mr. DRINAN. The gentleman from Ohio, Mr. Kindness, is recognized.

Mr. KINDNESS. Thank you, Mr. Chairman.

Thank you, Doctor. I really benefited greatly by your testimony here this morning.

On a personal experience level, have you found occasion very often in your practice to discuss with patients the content of their medical records or psychiatric records or to give them complete access to that record?

Dr. BEIGLER. In my own practice so far it has not been necessary. No patient has asked. I believe that is because of the nature of the relationship. Most of what transpires between me and my patients is out in the open.

When it comes to insurance claims practices or insurance applications, then I do not fill those things out without direct consultation with the patient and showing the patient exactly what I have put down with his cooperation and approval.

Mr. KINDNESS. In the area of patient access, I would think there would be considerable variation in terms of the degree of responsibility or ability to cope with the information contained in the records that you maintain for your patients. Would you care to comment in this area as to the dangers to the treatment process that might evolve from that?

Dr. BEIGLER. Yes, gladly.

During the deliberations of the Illinois law this point came up very early. The Illinois Psychiatric Society strongly supported the position of allowing access or providing for access by the patient. In most instances—I would say in over 99 percent of the cases—where there is a working relationship between the psychiatrist and the patient, and the patient wants to have access to the record, except for those personal notes where third parties have given information in confidence, then it would help the treatment process for the doctor to sit down and go over the chart with the patient. That would be part of the working relationship.

We supported strongly the provisos in the Illinois law for access by the patient.

There was one particular and somewhat amusing incident which was one of the first cases that came up in a State hospital where a patient wanted access to her records. Evidently she was under the stimulus of a civil libertarian legal advocate who thought the patient's rights should be protected. They went through a rather elaborate procedure to have the patient have access to her records.

When in the conference room this record was brought to her with her lawyer and some of the representatives from the hospital,

the patient took the record, tore it up, and threw it up in the air. That is an extreme example of the other end.

However, in most instances I would say that it would be helpful to the therapeutic process in a working relationship with an intelligent or competent patient to go over the record in a helpful way.

Mr. KINDNESS. If there were a provision for patient access on a fairly unlimited basis, would that tend to have an effect upon your practice as to what you would include in the records maintained?

Dr. BEIGLER. Certainly. Again, it is a complex situation. There are multiple rights involved here.

Some years ago I took considerable pride, because of my training and my sense of responsibility to train future physicians, to make a complete record, a rather extensive one, so that working in a teaching hospital there would be available to students, residents, and other doctors cases for clinical conferences and that sort of thing. One of my first hospitalized patients was covered by hospital insurance. Therefore, I wrote up one of these well-documented case histories in the process of an insurance claim and included the childhood history, the background of how this patient got to be the way he is, hopefully with the idea of educating people in the insurance processing office. I was naive at the time.

The claim was rejected on the basis that because I had put in that this dated back to childhood and included some of the formative problems that led to the adult problem, the insurance company declared, therefore, this condition had existed before the insurance was taken out and disallowed the claim. Since that time, I do not write as extensive a clinical history.

If I know the patients are going to have access, then I would have to be more circumspect about the things that I write, and yet have also in mind that there might be legal considerations so that I need to have adequate records as far as future responsibilities are concerned.

It is a complex thing, but the trend would be to lessen the amount of information that is put into the record.

Mr. KINDNESS. With an accompanying, presumed detriment to the treatment process possibly and the teaching process?

Dr. BEIGLER. I think teaching, yes, and therefore quality of training would be affected. However, I do not know what the specifics of that would be.

We still convey what goes on verbally. We do have our memories and that sort of thing.

Mr. KINDNESS. Do you see any merit to the thought that there would be a possibility of establishing two levels of confidentiality in different types of records? Would it be at all practical that there would be maintained a basic sort of record to which access might properly be obtained in the manner we are talking about? The other type of record, like the personal notes, would just not be available. It would not be subject to legal process or disclosure to any third party.

Dr. BEIGLER. That is stipulated in the Illinois law. We have only had 3 months of experience with it, but so far we have had no reason to regret it. In fact, we think this will be a step forward because there is an attempt made to draw the line to allow for access, reasonable access, by third parties and patients to the

record, as is required for constructive purposes. Yet, at the same time, the personal notes provisions allow for the maintenance of this. For example, personally I would like to keep my own thinking process and my speculations that would really be out of context in the chart available to the patient or to an insurance company.

For my own research purposes and writing and teaching, I have to have somewhat detailed notes concerning certain patients. It is a scientific resource.

If that material were discoverable, I believe it would be highly counterproductive in the long run to the interests of society.

Mr. KINDNESS. There is a part of your work and any professional work, I would think, that is yours and not the patient's.

Dr. BEIGLER. Yes, I would think so, because again that patient is benefiting from the knowledge gained from previous patients. There is sort of an implicit responsibility to future patients as far as that material being used for research purposes if it is protected as far as privacy is concerned.

Mr. KINDNESS. Thank you.

Mr. DRINAN. The gentleman from New York, Mr. Weiss, is recognized.

Mr. WEISS. Thank you very much, Mr. Chairman.

Dr. Beigler, I am not sure if you have worked this out totally. I certainly have not on the basis of your testimony, and perhaps I am even less certain now of the conflict than before. You seem to be suggesting at the outset of your testimony that in fact you have no problem at all with full patient access to records. Then in response to a later question by Mr. Kindness, I think you are suggesting that in fact there ought to be something like a dual set of records. I wonder if you recognize that conflict. Have you had occasion to discuss that with any of your patients or with any of the legislative people in Illinois to see what the general attitude seems to be toward that kind of really not full access, but limited access or dual access?

Dr. BEIGLER. If I conveyed the idea that I supported complete access to all records by patients, then I misspoke. There are two exceptions in my own thinking.

There is a small percentage of patients to whom it would be counterproductive to have access to records because there are pieces of information given in confidence by third parties. Therefore, we have to make some provision.

Mr. WEISS. I think you made that clear.

Dr. BEIGLER. All right. Then there is sometimes information that is harmful to the patient, perhaps a diagnosis or a family history. Again it would be a matter of clinical judgment.

We recommend establishing what we call the clinical intermediary where the physician feels there is some problem with the patient having access, so that this clinical intermediary—for example, another doctor of the patient's choice—would go over the record and translate it. Either full access could be given or at least the doctor has established the fact that he has some reservations.

That provision is already part of the law, the Buckley amendment, on the access to school records by students and families. That provision is in that law—that a clinical intermediary be called in where there is a question of access.

Mr. WEISS. That would be in those instances where there would be reason to believe that there would be direct harm to the patient if you were to disclose?

Dr. BEIGLER. Yes.

Mr. WEISS. OK. What about beyond that? Are there circumstances beyond that?

Dr. BEIGLER. The other stipulation is this. If this were a problem for an atomic physicist, for example, of having lay access to the atomic physicist's records, it would all be jargon. Obviously it would be the kind of language that most of us would not understand.

A psychiatrist or a psychoanalyst uses language that sounds very much like English, but these are all technical terms. The legal profession does the same thing. Words that sound like English are really technical terms. There is legalese. We have "psychoanalese" or "psychiatrese." It would be confusing and completely off the mark for most patients to try to translate the language himself.

If I have on my records my speculations about what a dream means or the deeper significance of some of the material that the patient has brought out into the open, and the patient had access to that, it would be very confusing at best. Yet, if I do not have an avenue for recording some of this information for my studies, for my future reflection, or for my scientific work and writing, then I think I have done a disservice to the patient because other patients might benefit from the work that I do.

I believe there has to be some stipulation for reserving these personal notes. The legislators in Illinois were sympathetic and enacted that proviso.

My friends with whom I have spoken, people who deal with families and the children's services bureaus, so far say that the thing works. When parents want access, they can have access to the factual material. Some of this confidential business or the speculations of the therapist and the providers is kept apart. Two sets of records are kept.

Mr. WEISS. Under Illinois law does that apply only to psychiatric medical records or does it apply generally to other providers of medical services?

Dr. BEIGLER. No. Only to psychiatric records.

Suppose you have a back injury and you want access to your records. You get all the records. You get the lab results and the X-rays. The doctor goes over it with you. You are only dealing with hard facts, tangibles.

However, when you are dealing with psychiatric material, it is intangible and subject to interpretation. You are dealing with a lot of intimate things. It becomes rather complex.

It is not the same as a banking record, an insurance record, or a hard medical record.

Mr. WEISS. Is the Illinois law part of a comprehensive piece of legislation that deals with all kinds of medical records or does it only deal with psychiatric medical records?

Dr. BEIGLER. Psychiatric and social service records. Let's see, it is called Mental Health and Developmental Disabilities Confidentiality Act.

Mr. WEISS. Are you then suggesting for our consideration that at the Federal level there also ought to be that kind of special consideration or treatment or provision for mental health records?

Dr. BEIGLER. Right.

Mr. KINDNESS. Might I insert a question at this point?

With respect to disclosure to a third party, an insurance carrier or an employer might have to have that much information that identifies the diagnosis in order to support the claim. However, even that disclosure, if misused so as to get beyond the anticipated bounds of use, could be harmful to a psychiatric patient as well as a medical patient generally, I suppose.

Dr. BEIGLER. Yes.

Mr. KINDNESS. Do you have any further specific thoughts with respect to what ought to be the guidelines, however established—Federal or State, statutory or regulatory—on the use of information once it is disclosed by the health care provider to the initial user of that information for necessary purposes?

Dr. BEIGLER. Would you please restate that question?

Mr. KINDNESS. Yes. What sort of guidelines should that third party have to follow with respect to the use of that information in your view?

Dr. BEIGLER. We have had rather extensive experience and deliberations on that particular point. We feel strongly that the patient should have control over what is done with the information that applies to him.

We happen to be in the middle of negotiations with the Department of Defense, CHAMPUS program for medical benefits to dependents of armed forces personnel, also currently with the PSRO's (Professional Standards Review Organizations). Regulations are currently being published which allow access by the Secretary of HEW to the deliberations of the Professional Standards Review Organizations.

If that occurs, then there is no control over the re-release or redisclosure of that information to some other agency. For example, if HEW is allowed by regulation to have access to the deliberations of PSRO's, then there is no control over what happens to that information after it gets to them. It is similar with law enforcement agencies or with CHAMPUS. Once those records are released to the Department of Defense, for example, then there is no control by the patient over what happens.

We recommend that there be no redisclosure without informing the patient, thereby he controls to a degree what happens to the information.

One of the buzz expressions on this thing is "the privilege follows the paper."

Mr. WEISS. Dr. Beigler, does Illinois have a basic medical record privacy act?

Dr. BEIGLER. Yes.

Mr. WEISS. It does? I assume that preceded by some time the most recent mental health privacy act?

Dr. BEIGLER. Yes.

Mr. WEISS. How long, do you know? How long has that basic law been in effect?

Dr. BEIGLER. Ten or fifteen years. I don't know.

Mr. WEISS. At the time that the mental health privacy records legislation was adopted, what was the reaction of the general medical community?

Dr. BEIGLER. To the new——

Mr. WEISS. To the new legislation.

Dr. BEIGLER. They helped us have it passed. We have a close relationship with the medical society. Our people worked together to get this law passed.

Mr. WEISS. There seems to be a broad recognition throughout the medical community as well as the political community at large, the legislative community, that there was the occasion after the years of experience with the basic law for a special treatment for mental health. Is that right?

Dr. BEIGLER. Yes. The Illinois medical privilege law is very similar to other State laws. It has 15 exceptions to privilege. It works only if there is no litigation.

Mr. WEISS. Thank you very much.

Mr. DRINAN. I know counsel has questions. We are pressed for time and I want the members to hear Dr. Gordis. Counsel, do you have one or two questions or would you like to present them in writing later? You may proceed briefly.

Mr. GELLMAN. Let me ask questions on one series of topics. The APA model law permits a 12-year-old to inspect his medical records. Are all 12-year-olds mature enough to handle this responsibility?

Mr. DRINAN. Yes, in Illinois they are. [Laughter.]

Dr. BEIGLER. Did you know that in the Federal regulations, regarding the use of human subjects for research, the age of consent is 7?

Mr. GELLMAN. No, I did not.

Dr. BEIGLER. Originally in Illinois we advised an age of 16. Then the child psychiatrists and the child workers protested, feeling that age 12 was a more reasonable age.

Mr. GELLMAN. The problem is not so much with the child having access to his records, but with his being able to keep his parents from seeing his records. I would think, in a lot of cases with 12-year-olds, the parents would get very upset at being excluded.

Dr. BEIGLER. That is true. Yet, again it is a matter of balance. It is in the child's interest in some situations where they do have the right to have access to certain types of medical treatment without permission from their parents.

It would be incongruous not to allow them to have privacy of their own records. Again it is a matter of all of us becoming educated to the problem. Times are different now than they used to be. It is difficult and subtle as to where to draw the balance.

Mr. GELLMAN. What would you think of a proposal that provided for children between, say, 12 and 16, just to pick numbers out of the air, for children within those ages the doctor would have the right to make the decision whether they were mature enough to see their records or whether their parents should do it.

Dr. BEIGLER. I would have to think that one over, Mr. Gellman.

In the APA model law these are only guidelines and it is up to the local jurisdictions as to what the legislative realities are and what is the mood of that particular group who knows the specifics

of a given situation. It is only a guideline. We do not have any hard, dedicated position on the number.

Mr. GELLMAN. Thank you.

Mr. DRINAN. Thank you very much, Dr. Beigler. I commend you upon being so well informed and so devoted to privacy in this area.

The next witness is Dr. Leon Gordis, a professor of epidemiology at Johns Hopkins University School of Hygiene and Public Health.

Dr. Gordis, we have your statement. It will be made a part of the record. Please proceed in anyway that you think appropriate.

STATEMENT OF DR. LEON GORDIS, REPRESENTING THE SOCIETY FOR EPIDEMIOLOGIC RESEARCH, AND THE ASSOCIATION OF AMERICAN MEDICAL COLLEGES

Dr. GORDIS. Thank you very much, Mr. Chairman.

I think the most appropriate way to proceed is not to read the full statement at this hour.

Mr. DRINAN. Thank you very much for your patience in waiting.

Dr. GORDIS. It is my pleasure.

I would really like to concentrate on what may be some of the major issues. I assume that the members have had a chance or will have a chance to read the statement.

Mr. DRINAN. As I said, the statement in its entirety will be made part of the record.

Dr. GORDIS. I do appreciate the opportunity to testify. I will try to keep my comments brief to allow enough time for questions, if the members have any.

By way of introduction, I would like to mention briefly why I am here. I have been engaged in epidemiologic and population-based research now for over a decade. For 5 years I served on the Institutional Review Board of the School of Hygiene and Public Health at Johns Hopkins University. When I went off that board, I went on the Institutional Review Board of the Johns Hopkins School of Medicine and Hospitals, on which I am now.

I know that a good deal of the interest of the committee relates to the institutional review boards. I have had considerable experience over the past several years in that regard.

I was invited to speak here on behalf of the Society for Epidemiologic Research, which is the official organization of those engaged in epidemiologic research throughout this country. It has over 1,200 members. I have chaired its standing committee on privacy protection for the past several years. I am now present-elect of the society.

I have also been asked by the Association of American Medical Colleges to speak on their behalf on the same issue. The AAMC is the national voice of the 119 operational U.S. medical schools in this country and their students and more than 400 major teaching hospitals in the United States.

In the short period of time which is available I would like to describe for you very briefly how epidemiological research works. What are the requirements of such research? How can they be made consistent with the need for protecting the privacy and confidentiality of research subjects?

If I get a chance, I would like to comment briefly on H.R. 2979. I will not comment this morning on the President's proposal because

it has only recently been received. I would like to comment on it at a later time.

By way of introduction, I would like to emphasize that both societies that I represent this morning believe firmly in the importance of privacy protection and that this protection can be best accomplished through the regulations of the Department of Health, Education, and Welfare which are presently in force and through new legislation, such as H.R. 2979 which is largely based on recommendations of the Privacy Protection Study Commission.

I would like to take a moment to comment on what is epidemiology. It is not only a difficult word to pronounce, but I think the concept is a little bit difficult for many people.

The epidemiologist looks at diseases in populations and tries to understand what determines the distribution of diseases in population. Why are certain people at higher risk for a disease than other people?

The reason for doing this is that if we can identify factors in the environment that are associated with the disease and we can reduce exposure to these factors, then we have real hope for preventing disease.

Therefore, we identify people at risk first to try to reduce environmental exposure. Second, if we can identify people who are at risk for a disease, even if we cannot prevent the disease, we can put them under close medical monitoring so that their disease can be picked up earlier and hopefully in a more treatable condition.

This is the rationale of applying epidemiologic methods to studying diseases that are of major public health importance. Many public health programs in this country—on infectious disease, cancer, cardiovascular diseases, and many other acute and chronic diseases today—have involved epidemiologic research. The investigation of Legionnaire's disease alluded to earlier involved epidemiologic research. The hazards of the swine flu immunization program could only have been identified through epidemiologic research.

Epidemiologic research is also used for evaluating the effectiveness of health care or looking at cost-benefit. If there is no benefit, there is no cost-benefit. Therefore, we have to demonstrate that a certain pattern of care or a certain method of providing care has a benefit to the patients who are receiving it.

Underlying all of this is the essential fact that the use of medical records is very, very important in carrying out any of these types of studies. They are important in studying the natural history of disease and in studies which evaluate the quality of effectiveness of care. In all these studies individually identifiable information is essential for carrying out this research. I will come back to that in just a moment.

I have listed in the written testimony on pages 6 through 8 a number of the major studies which have been carried out by epidemiologists which have made a major contribution to the health of the American people. For reasons of time I will not go through those, but they are available for your perusal later on.

I would like to emphasize that I believe society has a vital stake in these studies because the dignity and privacy of patients must

be protected at the same time that we advance the basic knowledge required for prevention of disease in our communities.

Epidemiologic investigations of the cause or the etiology of a disease, regardless of whether these studies deal with environmental agents, new medications that have been put on the market, the natural history of disease, or the effectiveness of preventive and therapeutic intervention, all require that with proper safeguards medical records with individually identifiable information be made available.

Why is that? How does an epidemiologist go about and do his work? Specifically, if an epidemiologist suspects, for example, that a certain occupation may be hazardous, then he has to be able to identify specific individuals who are in that occupational group. If he wants to investigate a certain group of people who have a disease to see whether they have a certain characteristic or a certain history of exposure, then he would have to identify people who have that disease.

Now identifying people is generally done through the medical record. He needs to know who those people are. If he does not have the identifiers, he cannot identify who those people are with the disease.

That is the first reason the identifier is necessary—to actually tell him who are the people he should be studying who have the disease in question.

Second, once he identifies these people—let's assume he identifies an occupational group—and he wants to know later on how many of them have died from cancer or from other diseases or how many of them have been hospitalized, then he must have identifiable information in order to link records from various sources. The second reason, then, is to link records on a given individual from various sources, which does require identifying information.

Finally, he needs identifying information because he usually has to compare the sick people he is studying with a group of normal people. Therefore, he needs identifying information on normal people so that he can understand the differences between those people who have a disease and those people who do not have a disease.

If he does not have the identifying information, he is unable to evaluate new approaches for prevention, detection, and treatment.

The identifier is critical. To have only the information in the record without identifiers is not sufficient.

The second point I would like to make deals with the issue of patient consent for use of medical records. This was an issue addressed earlier this morning.

There are a number of reasons why the requirement for patient consent before a legitimate investigator utilizes a medical record would make most medical research or epidemiologic research impossible. Very briefly, they are as follows:

First of all, many of these studies are carried out years after the patient was hospitalized. For example, take the case of girls who have developed cancer of the vagina after their mothers were exposed to diethylstilbestrol, DES, during pregnancy. These are girls in adolescence; 15 or 20 years after the exposure of their mothers, they have developed a very serious form of cancer.

Obviously at the time their mothers were admitted to the hospital the study could not even have been conceived. It would have been impossible to ask for consent. Therefore, the state of the art generally does not permit us to even conceive of a certain study at the time the patient is there even if we wanted to do so. That is the first problem.

The second problem is that we often do not know if a specific patient will, in fact, be included in the study. We must review the record and validate the diagnosis before we know if that is a patient who has a certain disease in question. If you asked the patient first, it would be a "catch-22" situation: You do not know if you need to ask that patient because you are not sure he has the disease in question, and yet you cannot look to see if it is the disease in question because you have not obtained the patient's consent.

Third, requiring prior patient consent would introduce the bias that if the patient said, "No, I don't want to be studied," you would not be able to determine whether there is a certain selection that has operated, so that the conclusions reached from a study might not be valid. I will get back to that if we have a chance.

On pages 11 through 16, I have outlined in a bit more detail some of the specific kinds of studies that would be very, very difficult or impossible to carry out were any of these restrictions in force. For reasons of time I will not discuss them, but they deal with problems of maternal and child health, with occupational diseases such as occupational cancers.

For example, we know that workers exposed to vinyl chloride are at a higher risk for liver cancer. Again, this could only have been found out by obtaining the records on a complete group of people exposed to vinyl chloride and a group of people not exposed, and comparing the rates of liver cancer in the two groups of people.

If we were not able to do this with identifiers—and without requiring each employee to give consent for use of his record it would be impossible to derive a meaningful conclusion about this type of cancer.

There are many problems today facing our society which require the use of epidemiologic research. I have addressed them briefly on pages 16 and 17.

However, I would like to comment on one specific problem. That is the effects of radiation. I think this is very much in the news.

I would like to direct your attention for a moment to the problem of the nuclear reactor accident in Pennsylvania. Here we have a group of people who have been exposed to some level of radiation. The question is: What is the hazard to which they have been subjected in terms of subsequent disease?

How do we go about answering that question? One way is to ask radiation scientists, physicians, and epidemiologists what they can tell us about the effects of low-level radiation. The fact of the matter is that we know that high levels of radiation are extremely hazardous, such as in people exposed to atomic bombs or other types of exposure. These people are at high risk.

What we do not know is what is the real hazard to people exposed to low levels of radiation. How do we get such information? We would have to study a group of people who had been

exposed to low levels of radiation and compare their subsequent risk with the group of people who had not been exposed to such levels. In order to do that you would have to have records on these people. You would have to know their names. You would have to obtain their hospital records. You would have to obtain death certificates if they had died and compare the rates of death and disease in both groups of people.

Several attempts are in progress right now to study the people who have been exposed to the nuclear bomb tests of many years ago and also to study workers in nuclear shipyards. The Department of Energy is now supporting such a study.

These studies are now in progress. they do require access to records without patient consent and the retention of identifiers during the time the study is being pursued.

Let's just suppose that 20 years from now—hopefully not—but let's say 20 years from now—another nuclear accident occurs. We would say we ought to be able to know what the hazard is because in 1979 there was an accident in Pennsylvania. How will we know what the risk has been to the people exposed to the nuclear reactor in Pennsylvania? Twenty years from now how will we have that information?

It seems to me that the only way such information will be available is by having a complete census of people who have been exposed to that reactor and a comparable group of people not so exposed and obtaining detailed medical information on them for the next decade or two to see whether there are any hazards in terms of congenital malfunctions, cancer, and other problems.

It seems to me that society has a tremendous stake in understanding the public health implications and the medical implications of this exposure, how serious it is or is not, but we will not have that information 20 years from now unless we make these records available for study.

Mr. DRINAN. If the Federal Government decided to make this survey you are suggesting of 50,000 people in Harrisburg, what State or Federal laws would inhibit such a study at this time?

Dr. GORDIS. I do not think it would be really inhibited at this time. I was really saying this in support of the legislation that Congressman Preyer has introduced.

We do have a model for this. The Center for Disease Control does investigate infectious disease outbreaks. These are usually acute and short term.

The problem is—and I think this is in response to one of the issues that has been raised—that many of the hospitals are quite confused about what they are allowed to release and what they are not allowed to release in terms of information. They do need some general guidelines because there is a great deal of lack of clarity. This is what we encounter doing such research.

I do not know Pennsylvania law per se. I do not know that there is any prohibition.

Mr. DRINAN. You stated on page 19 that this study, if it is going to be successful, should have "unhindered access to medical records including identifying information." Would that be available now?

Dr. GORDIS. In general, yes, by legitimate investigators. That is right.

Mr. DRINAN. Thank you very much. Please proceed.

Dr. GORDIS. I would like to comment very briefly on what goes on right now in terms of protecting confidentiality through the usual resources that we have.

I think all the members of the committee are aware that every institution that receives Federal funds has an institutional review board which must pass on all research that is carried out in that institution. These boards are responsible for protecting the rights of human subjects. Each investigator must submit a proposal through that board prior to the time that the application is funded. If money does come from a Federal source and that has not been approved by the board, then those funds are not made available to the investigator.

He must justify the rationale for subjecting any human research subject to any risk, including invasion of privacy, and must demonstrate to the members of the board what specific measures he is taking to insure the confidentiality of all personal and medical data in his possession. The board requires that the investigator show how he is protecting privacy of the medical records—the mechanics of how he is protecting the privacy, how the identifying information is going to be effectively separated from personal information about the subject during the research, at what point in the research, and how long the identifiers will be retained and for what reason, as well as what kind of security measures will be instituted.

The board reviews the consent statement that the patient makes. People who are receiving medical care are regularly assured that their care will not be jeopardized should they choose not to cooperate.

If there are further questions on the board, I can get into that later on.

I would like to comment specifically for a moment on the bill itself. We have reviewed it and find that the bill has many excellent provisions in it. I would like to just emphasize one example. This deals with the issue of redisclosure of information from one legitimate investigator to another. This is part of the bill. I would like to emphasize its importance.

I think that those who have drawn up the bill should be commended in its enlightened approach to the use of identifiers, to the nonrequirement of prior consent, and also on the re-release and disclosure. I would like to tell you why it is important.

For example, many communities have established cancer registries in recent years, which are full listings of cancer patients in a given community. One of the reasons for establishing a cancer registry is that if you have a group of patients with a certain cancer, they could be studied in order to try to define what the cause of the disease may be. That requires that the registry be able to re-release that information to a legitimate investigator, a bona fide investigator. If the registry could not do that, then most of the value of the registry would be lost. Re-release is crucial to most of the value of cancer registries in the United States today.

I would like to give you a second example of a less formalized structure. I have cited it on page 22 of my statement.

A large-scale study of births in the Province of Ontario, Canada, was carried out some years ago. A faculty member of our department was given access, through proper channels and with proper safeguards of confidentiality, and she investigated the relationship of maternal smoking to the health of the infant. A great many new and important findings came out of this study. They were not in the original study. They were not the original investigative intent. The original investigator was addressing a different issue.

However, the availability of this excellent data source for another investigator, after appropriate checks on privacy and confidentiality, made these data yield a new host of information regarding the impact in this case of smoking on the health of a newborn.

There are two points that I commented on regarding the bill which I would like to bring to your attention. One is the grouping together on page 25 of researchers, auditors, and evaluators in the first paragraph. I would like to point out that because the researchers are currently monitored by institutional review boards while auditors and evaluators are not, it was our view that it might not be advisable to group the three together because the needs are different for the three. Therefore, we have respectfully suggested what may not be proper prose, on page 23 of the testimony, a kind of paragraph that seemed to us to be appropriate for the research needs.

I would like to comment on one more issue. That relates to the protection of research data from subpoena. When we go out to interview a subject, we assure the subject that we will protect the privacy and confidentiality of what he gives us, the information he gives us. We adhere to that. We are very conscientious and scrupulous about it.

However, the fact of the matter is that we are not protected from subpoena. You have heard a good deal about that this morning.

I would like to raise the issue again of whether research data should have specific protections from subpoena except under extreme circumstances which militate otherwise.

In summary, I do think there is need for clarification of the situation of privacy in regard to hospitals and medical care providers. I think the contents of the legislation on a whole are excellent. I have mentioned some minor problems that I see. I believe that it is essential for there to be unhindered access to medical records for legitimate research. There should be no requirement of patient consent for record use provided there are safeguards for confidentiality. Identifiers must be available for investigators for reasons that I stated. Re-release to proper investigators should be permitted, provided that there are proper safeguards. There should be protection from subpoena.

Finally, I would like to commend the committee for emphasizing the use of the institutional review board for enforcing privacy standards. We believe that institutional review boards have been extremely effective, and one of the easiest ways of extending any regulations that are necessary is to strengthen them and use them for enforcement.

Thank you.

Mr. DRINAN. Thank you very much, Doctor, for your excellent statement.

I am happy to recognize the gentleman from New York, Mr. Weiss.

Mr. WEISS. I sense that even in your presentation and your advocacy of unhampered access that you do recognize the potential for abuse in this situation and that you really agree with the efforts that we make to try to reduce that kind of abuse which is possible in large-scale research efforts.

Are you satisfied that the institutional review boards really provide adequate safeguards along those lines?

Dr. GORDIS. I could only comment on the basis of my own personal experience both at my institution and at others where I visited for grant approvals or other reasons.

My experience has been very strongly in the affirmative. Obviously there are value judgments involved. These are difficult issues with which we are struggling.

Speaking from the experience of our own institutional review board, they grapple very diligently with each proposal that has any type of risk, including invasion of privacy. If the board has any question, the proposal reviewed is either sent back to the investigator or the investigator is invited to meet with the board to justify and give a rationale for what he is proposing to do. Very often he will be told that the safeguards for privacy and confidentiality are not sufficient that he is employing. He will be asked to rewrite his proposal putting in these safeguards.

My experience is that the efforts of the members of this board are extremely diligent and conscientious. The fact is they often differ from one another, but through creative discussion they protect the rights of the subject.

Mr. WEISS. Would it not be both possible and preferable to set forth what you would consider to be adequate safeguards within the statute itself rather than leaving it up to the differing interpretations of the various institutional review boards?

Dr. GORDIS. The Society for Epidemiologic Research is actually facing this issue of setting up safeguards within departments of epidemiology for the protection of confidentiality and privacy of subjects.

For example, we maintain all personal data in a locked file, but who will have access to the file? This is spelled out right now by the investigator to our committee, but we would like to get a general model regulation for departments that are carrying out this type of research. This could apply to agencies as well.

Let me give you a specific example. On an interview form that comes in, the patient's name is not put on the front page of the form but on an extra sheet. That sheet is removed from the interview. Only a study number links the two. The sheet with the patient's name is locked up. All work in analyzing interview data, unless it is absolutely necessary, is carried out using the study number. If somebody walks in, the information is completely impersonal.

Yet in the final analysis when it is necessary to link records from a given source, then the identifiers are still available.

Mr. WEISS. What you are saying is somewhat in line with some of the earlier testimony today from the American Medical Record Association.

You really do not need the names in many of these instances. Numerical identifiers would do just as well.

Dr. GORDIS. No. I would take very strong issue with the American Medical Record Association. With all due respect to the witness this morning, I suspect that her experience in carrying out population-based research is somewhat minimal and limited to the providing of records.

Those of us who carry out this research know, as I said earlier in my testimony, that it is essential for various reasons to have the identifier. First, it is important in order to know who the patients are. Second, it is important to be able to link records from different sources. These are the two major reasons for having the identifiers.

Operationally, while the project is carried out, we try to put the identifiers away under lock and key, but the principal investigator has access to them and frequent recourse to them. We protect the confidentiality of the record.

The studies themselves could not be carried out if the investigator carrying out the study did not have specific identifying information during the time the study is carried out. Results are reported only in aggregate. Identifiers are not retained after the study is done any longer than necessary, but during the time the study is carried out it is critical that the identifiers be available.

Mr. WEISS. Yet we had a recent horror story, of which I am sure you are aware, in New York. That confidentiality of the record-keeping was handled in such a slipshod manner that information was broadcast as to people who had received abortions.

Dr. GORDIS. Yes.

Mr. WEISS. So our concern—and I think yours and everybody else's—is very well taken and essential in this situation because unless we have fairly strict implementation, we are asking for a lot of trouble.

Dr. GORDIS. I agree with you completely. The New York situation was an extremely unfortunate one.

I might say, though, that to the best of my knowledge, despite the millions and millions of dollars going into medical and epidemiologic research in this country today, that is the only overt breach of which I am aware. You asked for recitation of horror studies. That does not justify that instance, but society essentially has to have a cost-benefit assessment of regulations it is going to implement, too. There are various ways of doing it.

To put a complete prohibition on identifiers is throwing out the baby with the bath. I think we have to look at why that happened and see what safeguards can be built in, but not make it so prohibitive that research cannot be carried out, even reasonable research that is in the best interest of society. We are trying to reach a balance on this.

Mr. WEISS. Thank you, Mr. Chairman.

Mr. DRINAN. The gentleman from Ohio, Mr. Kindness, is recognized.

Mr. KINDNESS. Thank you, Mr. Chairman.

In the interest of time I will state my problem and ask for your comment on it. My problem is with respect to a latter comment in your testimony about the protection of research data from subpoena. It does seem to me that in most instances the research data would

be second- or third-hand hearsay at best, thus would presumably not have a value to be used in court as evidence but might be used in the way of a fishing expedition in the discovery process before trial.

Would you comment on that, please?

Dr. GORDIS. Not being a lawyer, I really cannot respond to that. It may very well be so.

Mr. KINDNESS. I guess what I am really asking is this: Is it a real problem?

Dr. GORDIS. It is a real problem. There are specific protections now, I believe, for information in the area of drug abuse but that is limited. If a person would relate a criminal act, for example, in the course of an interview, as far as I know there is no protection.

To what extent it is a serious problem I really do not know. However, as I say, it is a problem in the drug abuse area sufficient that I understand there is a Federal protection for drug abuse data. I do not know if that is the only area, but that is the only one I know of where there is a specific protection. It must have been enough of a problem to militate a specific protection against subpena there. How extensive this problem is I really cannot say, but I did want to bring it to the attention of the committee.

Mr. KINDNESS. Thank you.

Mr. DRINAN. Thank you very much, Dr. Gordis. We thank you for your testimony. We thank you also for your patience.

We would talk longer here, but the bells are ringing to summon us to other duties.

[Correspondence follows:]

THE JOHNS HOPKINS UNIVERSITY

SCHOOL OF HYGIENE AND PUBLIC HEALTH

DEPARTMENT OF EPIDEMIOLOGY
Telephone: (301) 955-3286

615 North Wolfe Street • Baltimore, Maryland 21205

May 30, 1979

Congressman Richardson Preyer
Chairman
Government Information and Individual
Rights Subcommittee of the
Committee on Government Operations
Congress of the United States
House of Representatives
Washington, D.C. 20515

Dear Congressman Preyer:

My apologies for the delay in my responding to your kind letter of April 16th.

In regard to the specific question you raise requesting documentation of the fact that certain institutions are concerned about possible liability for non-consensual disclosures of identifiable medical records, the problem has been that in our experience, when institutions have such a concern, they generally do not voice such concerns in writing but rather just refuse permission. However, our personal contacts with hospital administrations and medical records room personnel have indicated to us verbally, that the basis for the hospital's refusal is often such a concern.

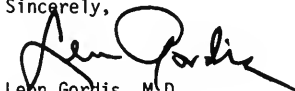
Recently however, in connection with a study being carried out in our department, we received a letter from one of the Baltimore hospitals we approached asking to review medical records. I believe the short excerpt I will present will demonstrate to you that concerns about liability are in fact, quite real. The letter, addressed to one of our faculty and signed by the Vice President for Medical Affairs of this hospital, read in part as follows:

"I am responding to your letter of April 27th, 1979 requesting permission to review the medical records at _____ hospital as part of the research study. At the advice of the hospital attorneys we have adopted the following protocol in regard to this type of request.

Before _____ hospital releases such information to any outside researcher, the researcher must sign an agreement that in consideration of permission to review and to use patient records maintained by _____ hospital, the researcher agrees to maintain the confidentiality of any patients identified and to use the records only for research purposes specified in its request for access to the records. Furthermore, the researcher and his sponsor should agree to indemnify _____ hospital against any claims made by any patient as a result of such release."

On another issue I should also like to point out that, as I stated in my testimony, the use of medical records is often the only starting point for identifying patients with a disease or a comparison group without a disease and contacting them and with their informed consent, obtaining further information through interview or questionnaire. I believe that it will be important for any legislation to clearly state that with the hospital's approval, it is legitimate for an investigator using medical records to contact the subject (or next of kin of the subject) identified through those records and ask for their participation in further studies. I believe that an explicit statement of this would be extremely valuable and important.

Sincerely,



Leon Gordis, M.D.
Professor and Chairman

LG/bb

Mr. DRINAN. The subcommittee stands adjourned.
[Dr. Gordis' prepared statement follows:]

RESEARCH USING MEDICAL RECORDS: ITS IMPORTANCE
TO THE HEALTH OF THE AMERICAN PEOPLE

STATEMENT PRESENTED TO
THE GOVERNMENT INFORMATION AND INDIVIDUAL RIGHTS SUBCOMMITTEE
OF THE COMMITTEE ON GOVERNMENT OPERATIONS
OF THE U.S. HOUSE OF REPRESENTATIVES

April 9, 1979

by

Leon Gordis, M.D., Dr. P.H.*

on behalf of the

Society for Epidemiologic Research

and the

Association of American Medical Colleges

*Address: Department of Epidemiology
Johns Hopkins University School of Hygiene & Public Health
615 N. Wolfe St.
Baltimore, Md. 21205

Telephone: 301-955-3286

1. INTRODUCTION

It is an honor and privilege for me to appear before this subcommittee in connection with its consideration of H.R. 2979, the Federal Privacy of Medical Records Act.

First, I would like to say a few words about my own professional background to help explain to the Committee my qualifications for testifying this morning. I am a Professor of Epidemiology and Chairman of the Department of Epidemiology at The Johns Hopkins University School of Hygiene and Public Health. I also hold a joint appointment in the Department of Pediatrics in The Johns Hopkins School of Medicine. I have a Medical Degree and Masters and Doctorate Degrees in Public Health. I am a board-certified pediatrician and a member of a number of professional societies including the American Pediatric Society, the Society for Pediatric Research, the American Epidemiologic Society and the Society for Epidemiology Research. I have been actively engaged in epidemiologic and pediatric research for more than a decade. In addition, for five years, I served as a member of the Committee on Human Volunteers of The Johns Hopkins University School of Hygiene and Public Health, and am now a member of the Joint Committee on Clinical Investigation which is the Institutional Review Board of the Johns Hopkins School of Medicine and the Johns Hopkins Hospital. In accordance with the guidelines of the Department of Health, Education and Welfare which are currently in force, this committee is charged with protecting the rights of human research subjects and guaranteeing the confidentiality of all personal and medical data obtained in the course of any research investigation.

This morning I am testifying in a dual capacity. First as a member and representative of the Society for Epidemiologic Research. This society is the official organization of those engaged in epidemiologic research throughout this country and has over 1200 members. I am presently President-Elect of the Society and serve as Chairman of its Standing Committee on Protection of Privacy in Epidemiologic Research.

In addition to representing the Society for Epidemiologic Research this morning, I am also here as spokesman for the Association of American Medical Colleges (AAMC) formed in 1876 to work for reform in medical colleges. It has broadened its activity over the years so that today it represents the whole complex of individuals, organizations and institutions charged with the undergraduate and graduate education of physicians. It serves as a national voice for all of the 119 operational U.S. medical schools and their students, more than 400 of the major teaching hospitals, and 60 learned academic societies whose members are engaged in medical education, biomedical research and the delivery of health care. Through its members, the concerns of the Association range far beyond medical education itself and include the total health and well-being of the American people.

In the time allotted me this morning I should like to do several things: First, I should like to describe very briefly the scope of epidemiologic research and its importance for the health and well-being of the American people. Second, I should like to demonstrate how essential the use of medical records has been in the past in a number of landmark epidemiologic studies which have made invaluable contributions to the health of our citizens. Third, I should like to indicate some

of the important health problems we now face which desperately need knowledge gained from epidemiologic research if these problems are to be prevented and controlled, and how essential the use of medical records is for carrying out the studies needed in these areas. Fourth, I should like to describe to you briefly the safeguards which are currently in effect for protecting the rights of human research subjects and the confidentiality of their personal information, including that in medical records, during the course of a research project. Finally, I would like to comment specifically on H.R. 2979, The Federal Privacy of Medical Records Act. Since the President's message to Congress on Privacy Policy, including a draft of the proposed "Privacy of Medical Information Act", has only recently been received, I shall not discuss it this morning, but would like to submit specific comments on it at a later date.

I should like to emphasize that the members of the Society for Epidemiologic Research and of the Association of American Medical Colleges are fully committed to protecting the confidentiality of the medical and personal data they obtain in the course their research activities and share a deep concern for the protection of all people who participate in medical and epidemiologic research. We believe that privacy protection can best be accomplished through the Department of Health, Education and Welfare regulations presently in force and through new legislation such as H.R. 2979 which is largely based on the recommendations made by the Privacy Protection Study Commission in its report to the Congress entitled, "Personal Privacy in an Information Society".

2. Epidemiology and the Nation's Health--The Need for Using Medical Records

Epidemiology may be defined as the study of the distribution and dynamics of disease in human populations. Its purpose is to identify specific agents or factors related to people and their environments which may be the cause of disease or which may identify people who are at high risk for developing a disease. In so doing, epidemiology provides the basis for public health programs designed to prevent and control disease. Prevention can be effected by reducing or eliminating people's exposure to a specific factor, once its importance in producing disease has been demonstrated. Identification of people at high risk for disease is important for two main reasons: First, so that measures can be adopted to prevent their developing disease and second, to provide medical supervision and screening tests where appropriate so that if they do develop disease, their illness can be identified at a very early stage when it can be successfully treated.

The public health programs made possible by knowledge gained from epidemiologic investigations include those directed at prevention and control of infectious diseases, and of cancer, stroke, heart and other cardiovascular diseases, and many other acute and chronic conditions which affect the American people. Investigation of "Legionnaire's Disease", for example, required an epidemiologic approach. Epidemiologic methods are also essential for evaluating the efficacy of new preventive and therapeutic measures as well as their possible harmful side effects. For example, the possible harmful effects of swine flu immunization required epidemiologic investigation and indeed, these investigations

were responsible for demonstrating the relationship between immunization and development of the Guillain-Barre syndrome.

Epidemiologic methods are also needed for determining the effectiveness of new organizational patterns for delivering health care. In addition, those of us who are concerned with the question of cost-benefit in health care recognize that the issue cannot be reasonably discussed by focusing only on cost. For in examining cost-benefit of any type of health care, one must first demonstrate that it, in fact, has a benefit, and such a demonstration requires the use of epidemiologic methods.

In this context, I should like to direct this Committee's attention to the invaluable contribution of medical and vital records to various types of health-related research. These records are used in epidemiologic investigations, in longitudinal studies of the natural history of disease, and in studies which are designed to evaluate the quality and effectiveness of health care delivered to the community. In addition, I should like to stress that individually identifiable information in medical records is essential for conducting epidemiologic studies. It is necessary so that the records can be used as the basis for identifying individuals with a certain disease and individuals without the disease--some of whom may have had their disease many years prior to the time of the study--so that these individuals can be followed up through interviews, questionnaires or other methods. Individually identifiable information is also necessary in order to link records from different sources which pertain to a given individual. Thus, for example, in

investigating whether a new form of treatment improves survivorship, it is necessary to link hospital records with death certificates for each individual receiving the new treatment and for each individual not receiving the new treatment so that the death rates in both groups can be compared.

3. Some Major Health Studies Which Have Required Use of Medical Records

Epidemiologic inquiry depends on the availability of the medical and vital records of large numbers of people, both for the data that they contain as well as for ascertaining and identifying individuals for subsequent interview and study. The major contributions of epidemiology to our understanding of disease have been based on studies using data from such sources, studies sometimes conducted many years after the information was recorded. These contributions can be demonstrated by a few selected examples of past investigations which have elucidated the causes of human diseases and facilitated their prevention. Many would have been virtually impossible to carry out had medical and other records which included identifying information, not been available to investigators. Among these studies are:

1. Cancer

Studies which demonstrated:

- the relationship of cigarette smoking to lung cancer as well as to coronary heart disease, bladder cancer and other conditions.

- an increased cancer risk associated with occupational exposure to substances such as asbestos, vinyl chloride and arsenic.
- the increased risk of several types of cancer after exposure to radiation.
- that the daughters of women who received the hormone diethylstilbestrol (DES) during pregnancy have an increased risk of developing cancer of the vagina many years later.
- that women taking estrogens for menopausal symptoms are at increased risk of endometrial or uterine cancer.
- the effectiveness of breast cancer screening in reducing mortality from breast cancer.

2. Cardiovascular Diseases

Studies which demonstrated:

- that high blood fats, high blood pressure and smoking shorten life expectancy, particularly through early death from coronary heart disease.
- that women taking oral contraceptives are at increased risk of developing thromboembolism or stroke.
- the benefit of early detection and treatment of hypertension.
- that administration of anticoagulants to patients with myocardial infarctions is associated with lower post-infarction mortality rates.

3. Infectious Diseases

Studies which:

- led to the development of vaccines for poliomyelitis, measles and other infectious diseases.
- showed that cases of polio which developed subsequent to polio immunization in 1955 resulted from a vaccine lot having been contaminated with live virus.

4. Health of Children

Studies which demonstrated:

- that the administration of high concentrations of oxygen to premature infants results in blindness.
- that maternal rubella (German measles) infection during pregnancy produced congenital malformations in the infant.
- that the use of thalidomide during pregnancy results in severe congenital malformations of the arms and legs of infants.
- that maternal radiation exposure during pregnancy is associated with an increased risk of childhood cancer and congenital malformations.
- that Rh disease (erythroblastosis fetalis) in newborns can be prevented.
- that inner-city comprehensive care programs for children and youth are effective in reducing rates of rheumatic fever.

These are but a handful of the important studies which have produced direct benefits for human health by identifying the causes of disease, facilitating the development of preventive methods, and evaluating

new ways of providing medical care and organizing health care delivery. It would be tragic indeed if the potential benefits to society of such research were lost as a result of any restrictive approach which in essence would make such studies impossible.

Society has a vital stake in these types of studies. Society as well as the affected individuals must bear the costs of disease. Consequently, society must ensure that a reasonable approach will prevail, in which the dignity and privacy of patients will be protected while the advancement of knowledge of disease through epidemiologic investigation will be facilitated. The social contract which facilitates the existence of communities as social groups, requires that each individual yield some of his individual rights, including confidentiality and freedom of action, for the benefits of society as a whole. Compliance with traffic regulations and with income tax laws are but two examples of the interactive workings of the social contract. Each society must decide when a limited compromising of individual rights is justified by the potential benefits to be derived by the community as a whole. Epidemiologic investigations of the etiology of a disease--whether dealing with environmental agents, newly developed medications, the natural history of a disease, or the effectiveness of preventive and therapeutic interventions--are of great potential benefit to society and its members. The conduct of such studies, however, requires that, with proper safeguards, individually identifiable data from medical and other records be made accessible for purposes of legitimate medical and epidemiologic research without requiring prior patient consent.

4. How Epidemiologic Investigations Are Carried Out Using Medical and Other Records

a. Why Identifying Information is Essential For Such Research

In order to carry out epidemiologic research it is often necessary to identify individuals with specific diseases or disabilities, or individuals who share some common environmental exposure. Medical records are essential for identifying populations with specific diseases and for obtaining detailed historical, clinical and laboratory information about the patients. Individually identifiable information is essential in these studies, because access to these records is only a first step in ascertaining and identifying patients with the particular disease under study so that they can be subsequently contacted, and with their informed consent, interviewed and studied. Identification of specific individuals during the time the research is conducted is also essential to link records on a given person from different sources, such as physician records, hospital records, employment records, and birth and death certificates. Furthermore, since groups of patients with a particular disease must be compared with groups who are non-diseased or who do not have the particular disease under study, in order that meaningful inferences about the causes of the disease can be derived, identifying information about non-diseased and non-patient subjects must also be available. This approach is fundamental to epidemiologic studies of the etiologic and risk factors of disease, to studies of the natural history and prognosis of disease, to the evaluation of new approaches to prevention, early detection and treatment, and to the evaluation of new methods for delivering health services.

b. Why Requiring Patient Consent Would Make Most Studies Impossible

It is important to point out that such research would be virtually impossible to carry out if patient consent were required in order for the investigator to have access to medical records. Since the studies described above were frequently conducted many years after the original medical information was recorded, the state of knowledge at the time the information was obtained from the patient may not even have permitted the study to be conceived, so that patients' consents could not possibly have been obtained. In addition, reviewing medical records is often only the first step in ascertaining and identifying patients with a given disease so that they may be subsequently traced, contacted and with their permission, studied further. Any requirement that consent be obtained before any medical record is reviewed would be extremely destructive to medical and epidemiologic research and consequently would be profoundly damaging to the maintenance and improvement of the health of all Americans.

5. Some Specific Examples

a. DES and Vaginal Cancer

In order to convey some idea of just how important the legitimate research use of medical records is, I should like to cite a few major findings from several epidemiologic studies. First, I should like to refer to the studies dealing with diethylstilbestrol or DES as it is known. These studies of the effects of DES in human beings are particularly important since for many years DES was added to livestock feeds in the United States. A few years ago, investigators in Boston demonstrated

through an epidemiologic study, that when mothers took DES during pregnancy to prevent a miscarriage, female offspring of these pregnancies were at increased risk of developing a rare type of cancer of the vagina when they reached adolescence.

This study could only have been carried out through the use of medical records. Three particular features are noteworthy here: First, the cancer did not appear in the person taking the medication but only in her female offspring exposed to DES during intrauterine life. Second, the cancer appeared some 15 to 20 years after exposure to DES so that it was necessary to go back many years to determine exposures and to identify the drugs taken in pregnancy. Third, in this study, the girls and young women who had this cancer were first identified from their medical records, and only then could their mothers be contacted and followed-up. Consequently, if use of medical records were prohibited, or if such use were permitted only with the consent of the patient, these studies which demonstrated the cancer-producing effect of DES in women many years after exposure, would have been impossible to carry out.

This study is perhaps the first demonstration in human beings of transplacental carcinogenesis, i.e., that cancer-causing agents taken by the mother can cross the placenta and produce cancer in the offspring. There may be other such agents--presently unknown--which mothers should avoid during pregnancy because of the hazard to their children. In order to identify these agents, thorough epidemiologic investigations using medical records are needed to protect the health of American women and their children. This is an area which could not be explored, however, if restrictions were placed on research uses of medical records.

b. Occupational Cancers

I should like to turn next to another important area--the health of the American worker. In recent years, there has been increasing recognition that Americans employed in industries are often subjected to high concentrations of potentially toxic substances. Thus, for example, workers exposed to vinyl chloride have been shown to be at high risk of liver cancer. This finding, which has now been confirmed in a number of studies, could only be made by reviewing the medical records of large groups of employees in specific industries and linking the employees' records at the factory site with hospital records and death certificates if they exist. Without access to these records it would be impossible to have identified vinyl chloride as a cause of cancer in occupationally exposed human beings. I should also point out in this connection, that if there were a requirement that patient consent be obtained before the records were made available--these studies could also not have been carried out because many patients had either died by the time the study was done or else had moved and could not be traced.

It is clear that we have only begun to scratch the surface in terms of the toxic and cancer-producing potentials of substances to which American workers are exposed in the course of their daily labors. Any restriction which would preclude the possibility of identifying new damaging substances and documenting their harmful effects would be a major setback to the protection of the health of the American worker.

c. Preventable Blindness in Premature Infants

I should like to turn briefly to a tragic medical story which unfolded during the 1950's. At that time premature infants who were of

low birthweight, were found to have an increased risk of a form of blindness called retrolental fibroplasia. Surprisingly, the risk of blindness was highest in the best medical centers in our country while in the less sophisticated and less well-equipped medical centers, the risk seemed lower. Initially there was no clue as to what might be causing this blindness and numerous investigations in many areas were carried out. However, epidemiologic investigations subsequently demonstrated that the cause of this blindness was high oxygen concentrations administered to the premature newborns. These high concentrations were often only provided in the best medical centers, since at that time, the highest possible oxygen concentration was considered the best medical care for these infants. Since that time, restriction of the oxygen concentration to a lower level when administered to premature infants has virtually wiped out this form of blindness in prematures. Again, these studies which demonstrated that high oxygen concentrations were the cause of blindness in children and that reducing these concentrations could prevent such blindness, would have been totally impossible to carry out were access to medical records restricted.

d. Benefits of Anticoagulant Drugs For Patients with Heart Attacks

For many years, there has been a difference of opinion among physicians with regard to the possible effects of anticoagulants in the treatment of patients who have heart attacks. Several years ago, we carried out a study in which we reviewed the records of a large number of patients who had had heart attacks and who had been hospitalized

some years previously. We ascertained which patients had received anticoagulants and which patients had not, and then determined which patients had died during their hospitalizations. We were able to show that the death rate was much lower in patients who had received anticoagulants during their hospitalization than in those who had not. This important observation has now been confirmed in another study carried out in our Department. We believe that in the coming years, these findings will have major implications for the care of heart attack victims. Yet both studies could not have been carried out without the use of medical records and identifying information, and would have been impossible had the consent of the patient been required for reviewing these records.

e. Harmful Effects of the Pill (Oral Contraceptives)

Although the "pill" has been demonstrated to be a highly effective and convenient form of birth control which has been adopted by many American women as their form of contraception, a large number of epidemiologic studies have now demonstrated that women taking the pill for long periods of time are at increased risk for blood clots, strokes, heart attacks, high blood pressure, liver tumors, gallbladder disease, congenital malformations in their offspring and other conditions. These highly significant findings were in large measure the result of large-scale studies which used hospital and medical records--studies which again would have been impossible to carry out if patient consent had been required. The pill studies are examples of studies of the adverse effects of many drugs which are critical for protecting the health and well-being of the American public.

f. Improved Survival of Children with Leukemia

One of the greatest accomplishments of American medicine during the past decade or two has been the breakthrough in the treatment of acute leukemia in children. While children with leukemia at one time died within a few months after diagnosis, with the new advances in therapy, they now live many years--and are often free of any evidence of their disease. The demonstration that new forms of therapy have resulted in an improved outcome such as this for the patient also requires the use of medical records.

6. Meeting Current Challenges to the Health of the American Public--
The Need for Research Using Medical Records

Among the major public health problems today in the United States are those of cancer, cardiovascular disease and other chronic conditions, as well as infectious diseases such as hepatitis, venereal diseases and influenza, and the evaluation of the benefits and possible risks of new vaccines. Much of cancer today is probably environmentally determined. In an interview some time ago, Dr. Arthur C. Upton, Director of the National Cancer Institute, responded to a question about research needs in the cancer field, saying, "We need a lot more good epidemiology. It can tell us not only about environmental factors but also about genetic influences and we really do need to know about both." Dr. Upton's comments apply just as well to cardiovascular diseases, including coronary disease, high blood pressure and stroke, neurological diseases including epilepsy, as well as to diabetes, arthritis, digestive diseases and virtually all other chronic conditions in this country. In addition, the effects on human health of new drugs and other chemicals in the environment which require close attention, if the health of the American

public is to be protected, can only be identified through epidemiologic and other investigations, most of which depend on the availability of medical records. Any legislation which would limit the availability of these records and would require patient consent, would seriously compromise medical and epidemiologic research in this country and would make most of these studies impossible. The result would be serious damage to the health of many Americans, and certain groups in particular, such as American workers, women and children would be left at high risk of exposure to toxic, cancer-causing or malformation-causing agents, without any form of protection. Thus, the maintenance and improvement of the health of Americans and their protection from environmental hazards, requires the facilitation of epidemiologic research and the continued availability of medical records. At the same time, confidentiality and privacy must be protected through the means discussed below.

7. A Specific Current Example: Effects of Radiation

I should like to give the members of this Subcommittee a more immediate example of how essential epidemiologic research based on medical and other records is. I should like to direct your attention to the recent nuclear reactor accident in Pennsylvania. One of the questions posed by this accident has been how serious is the potential risk to residents of the area who may be exposed to radiation from the reactor? We know that high levels of radiation are extremely hazardous to human beings by producing cancer, congenital malformations and other serious problems. What is not known with any degree of certainty is the extent of the hazard from low levels of radiation. In order to generate data on the hazard from such low levels of radiation it is essential that

information be collected on a population of people who had such a radiation exposure in the past. If such a population can be identified, we would then attempt to trace the members of this population and obtain any relevant physician records, hospital records, or death certificates. It would also be necessary to identify a non-exposed population and obtain similar records in order to determine the rate of disease in that population. Only in this way could we determine whether the exposed group has a higher rate of disease or a higher death rate than the group that was not exposed. In order to answer the question whether people who were exposed to low levels of radiation are at greater risk than those who were not so exposed, we would compare the rates of disease and of death in the exposed people with the rates in those who were not exposed. Such a comparison requires that, with proper provisions for the protection of privacy, medical and other records for the members of both groups be available for investigation. For the conclusions to be valid, complete records must be available on the entire group virtually without exception. Examples of populations which were exposed to radiation and are currently being studied in this way are individuals who were exposed to fallout from atomic bomb tests in the past and individuals who were employed in the naval shipyards.

Now, let us consider what might happen twenty years from now if another such nuclear accident occurred. We might want to know what were the effects--both short-term and long-term--of the 1979 Pennsylvania nuclear accident on people who were exposed to radiation which leaked from the reactor? How could this question be answered? The answer could come only if we were able to follow-up the total population of residents of the area around the reactor over a period of many years,

identify all episodes of serious illness and deaths in this group, and obtain similar information for a population that is comparable to the exposed population except for the fact that it was not exposed. These data would be extremely important in the future for assessing the seriousness of exposure to levels of radiation which leaked from the Pennsylvania reactor. In order to obtain these data, it would be necessary to have the names and addresses of all residents in the area, to have access to their medical and vital records with identifiers included, and to establish procedures for tracing, re-contacting and following up these people to determine all episodes of serious illness and death. If access to records is not facilitated for legitimate medical and epidemiologic research, the American people will be denied such information regarding radiation hazards. It is, therefore, essential that any legislation enacted by the Congress ensure that legitimate medical and epidemiologic researchers have unhindered access to medical records including identifying information. Such access, naturally, must be conditional on the demonstration by the investigator to his Institutional Review Board that he has provided adequately for protection of privacy and confidentiality.

8. Existing Safeguards for Protecting Confidentiality

I should like to comment now on the safeguards which are currently in force for protecting confidentiality. As studies are conducted, all epidemiologists and medical researchers have a major professional and personal responsibility to minimize invasion of privacy as much as possible, and to protect vigorously the confidentiality

of the data in their possession. The provisions of the National Research Act (P.L. 93-348) and its implementing regulations on Protection of Human Subjects, codify an elaborate system of safeguards, currently in operation within the scientific community, to prevent violations of the rights of patients for purposes of research. This system is complete with Institutional Review Boards which are responsible for protecting the rights of human subjects and to which each investigator must justify the rationale for subjecting any human research subject to any risk--including invasion of privacy--and must demonstrate the measures he is taking to ensure the confidentiality of all personal and medical data in his possession.

In any study, Institutional Review Boards serve to ensure that unnecessary invasion of privacy will not take place and that adequate safeguards will be provided for the confidential handling of data and that the use of individual identifying information together with the data will be kept to an absolute minimum consistent with carrying out the study properly. Investigators must assure the Institutional Review Board that the research data that they collect will be kept under lock and key, and they must inform the committee who will have access to the data, how and at what point in the research individually identifiable information will be effectively separated from other data and whether or not the data will be retained at the close of the study, and if so, why. Each Board thoroughly reviews interview instruments and questionnaires, the consent statement and any accompanying material which must be sufficiently informative to enable the subjects to decide on their participation freely and rationally. If the subjects are patients, they are regularly assured that their care will not be jeopardized in any way by their failure to participate and further, all

subjects are assured that they are free to withdraw from a study at any time. Many of these provisions are spelled out in the current regulations of the Department of Health, Education and Welfare.

It is thus apparent that epidemiologists and other medical investigators are keenly sensitive to the challenge of ensuring confidentiality and protecting human subjects, and as presented briefly in this section, already have an elaborate and effective system which protects the subjects and the confidentiality of their personal and medical data, and at the same time facilitates the conduct of medical and epidemiologic research so that the cause of improving the health of Americans will be advanced as rapidly as possible.

9. Comments on The Proposed Legislation

I should like now to comment specifically on Bill H.R. 2979.

After a thorough review of this Bill, we find that most of its provisions which bear on research uses of medical records, are well considered and thought out. The Bill wisely protects access to records by medical and epidemiologic investigators but at the same time pays appropriate attention to the needs for safeguarding privacy and confidentiality.

I should like to point out that the provisions in H.R. 2979 which allow re-release or re-disclosure of information for research or health statistics purposes provided safeguards of confidentiality and privacy are maintained, are extremely important. Permit me to cite a specific example. Because of the increasing importance of the problem of cancer in our country, many cities and states are establishing cancer registries. These are lists of newly identified patients with

cancer and they are designed not only to facilitate the long-term care of cancer patients but also to alert health officials quickly to clusters of new types of cancer which may be occurring and also to permit investigators to identify all patients with a given cancer so that the cause of that cancer can be investigated.

Cancer registries generally obtain their data from hospitals and pathology laboratories. Existence of a registry would be of very limited usefulness, however, if it were not possible for the registry to go the next step and make its data available to legitimate cancer investigators. Thus, re-release of information with appropriate safeguards is essential.

I should like to cite a second example. A large-scale study of births was carried out some years ago in Ontario, Canada. Subsequently, an investigator in our Department was able to utilize the data from that study to demonstrate a number of important relationships between a mother's smoking habits during pregnancy and the subsequent health status of her newborn infant. These findings were possible only because the data from the original study were made available some time later to another investigator. Throughout this process of re-release, rigid safeguards were maintained to protect the privacy and confidentiality of all data and identifying information.

I should, however, like to raise two specific points with regards to H.R. 2979. First, the first paragraph of Page 25 (b) (1) groups together researchers, auditors, and evaluators of identifiable medical record information. We believe that this grouping is inadvisable. Under current regulations, researchers are, in fact, already subject to

supervision by Institutional Review Boards in regard to protection of human subjects and the maintenance of privacy and confidentiality of personal and medical records. On the other hand, auditors and evaluators have no such supervision and therefore, the needs for protection of privacy and confidentiality for them differ from the needs for protecting privacy and confidentiality in regard to researchers. We therefore believe that in that paragraph, the word "researchers" should be eliminated from line 2 and again from line 8.

We respectfully propose that a paragraph along the following lines be inserted between lines 10 and 11 on Page 25 following paragraph (b) (1):

The secretary shall require that the assurance statements received from Institutional Review Boards contain adequate security standards regarding the use and maintenance by researchers of identifiable medical record information disclosed by facilities under Sections 124 and 125. These standards of the Institutional Review Boards shall include appropriate administrative, technical and physical safeguards for ensuring the security and confidentiality of these records.

I should like to make a further comment regarding another important issue. This relates to the protection of research data from subpoena. At the present time, in most research areas, no such protection is guaranteed. While an investigator may make the maximum effort to safeguard the confidentiality and privacy of information he obtains, such information may be subjected to subpoena by a court of law.

We therefore respectfully suggest that data obtained for research purposes be immune from subpoena except under very precisely stated extreme circumstances.

10. Summary and Recommendations

The issue of privacy and confidentiality is an important one which must be addressed by society. Epidemiologic and medical investigators whose goal is the improvement of human health and the prevention and control of disease, are keenly aware of this issue and operate under safeguards designed to protect human subjects participating in research and to ensure the confidentiality of the information they provide--be it through questionnaires, interviews or their medical records.

Continued epidemiologic and medical research is essential to improve the health of the American public and to protect all Americans, and in particular certain subgroups such as industrial and other workers, who are at high risk from old and new environmental hazards. Identifying the causes of disease in order to develop prevention programs, and evaluating the effectiveness of new preventive and therapeutic measures as well as new ways of organizing and delivering health and medical care, all require an epidemiologic approach which must utilize medical and hospital records. Access to such records must be unhampered, provided that the investigator provides adequate assurance to his Institutional Review Board, that privacy and confidentiality are being adequately maintained.

[Whereupon, at 12:20 p.m., the subcommittee adjourned, to reconvene at 10 a.m., Wednesday, April 11, 1979.]

PRIVACY OF MEDICAL RECORDS

WEDNESDAY, APRIL 11, 1979

HOUSE OF REPRESENTATIVES,
GOVERNMENT INFORMATION
AND INDIVIDUAL RIGHTS SUBCOMMITTEE
OF THE COMMITTEE ON GOVERNMENT OPERATIONS,
Washington, D.C.

The subcommittee met, pursuant to recess, at 10:07 a.m., in room 2247, Rayburn House Office Building, Hon. Richardson Preyer (chairman of the subcommittee) presiding.

Present: Representatives Richardson Preyer and Peter H. Kostmayer.

Also present: Timothy Ingram, staff director; Robert Gellman, professional staff member; Maura Flaherty, clerk; and Thomas Morr, minority professional staff, Committee on Government Operations.

Mr. PREYER. The subcommittee will come to order.

Today we continue our hearings on legislation to protect the confidentiality of medical records. Our first witness is Mr. Justice Horace Krever, Commissioner of the Royal Commission of Inquiry into the Confidentiality of Health Records in Ontario, Canada. Mr. Justice Krever is accompanied by Harvey Strosberg, counsel to the Commission.

When this subcommittee began serious consideration of the medical records issue last year, we discovered very quickly that the Canadian Royal Commission was well ahead of us. Through the kind cooperation of the Royal Commission's staff, we have been able to follow the progress of the Commission's investigations. The results have been very impressive, and I don't mind admitting that we are a bit jealous of the excellent job they are doing. No one in this country has compiled such a thorough record of the abuses of medical records.

On behalf of the subcommittee, I welcome both of you here today. We are very grateful that you were able to take time out of your busy schedules to share with us some of the evidence that you have uncovered in the last year. I know that it will be of tremendous assistance to us as we consider the need for legislation in this country.

It is a pleasure at this time to recognize Mr. Justice Krever and Mr. Strosberg. We will ask them to proceed in any manner they see fit.

STATEMENT OF JUSTICE HORACE KREVER, COMMISSIONER,
ROYAL COMMISSION OF INQUIRY INTO THE CONFIDENTIAL-
ITY OF HEALTH RECORDS, TORONTO, ONTARIO; ACCOMPAN-
IED BY HARVEY STROSBURG, COUNSEL

Mr. KREVER. Thank you very much, Mr. Chairman.

May I express my pleasure at being here and demonstrate my gratitude for all the assistance enthusiastically given to us by your staff, particularly by Mr. Gellman who has been the liaison between our staffs. I hope that cooperation which has been so evident will continue until we both have completed our tasks. If we can be of any assistance in the future, we will be only too happy to do so. All you need to do is ask.

Mr. PREYER. We appreciate that. We will be calling on you.

Mr. KREVER. If it would be more helpful for someone or all of you and your staff to come to Toronto to see first hand what we have acquired by way of information, you are more than welcome.

I want to begin with one word of qualification. Because I have not yet submitted my report, I am a little handicapped by the absence of freedom that I would have had if I had reported, in speaking my mind on policy matters. I will be happy to share with you all the factual information we have which is not in dispute. However, where there are disputed issues of fact, I will have to make findings of fact, and that is something for the future.

May I give you a little picture of our jurisdiction? To a national body of your dimensions we, by comparison, are really a microcosm. When you look at the figures that we may cite to you, I think it would be helpful to see what those figures are with relation to the entire population and other demographic features of Ontario. I know this may be insulting in a way perhaps to all of you, but for the record I think I should say something about our two different jurisdictions and the differences between them. Therefore, for the record I will preface my remarks with this explanation.

Canada is a Federal nation with 10 Provinces. We have no constitutionally entrenched bill of rights. Although we have a Federal statute called the Bill of Rights Act, it has no application to those fields in which the provincial legislatures are sovereign. The field of property and civil rights within the Province, of which privacy may be thought to be a part, is within the exclusive legislative jurisdiction of the Provinces.

The right of privacy—and I think this is an important distinction you should bear in mind—is not one in respect to which as yet protection has been given in the sense of the sanction of a recognized cause of action for damages for the violation of one's privacy.

Time does not permit a longer exposition of our constitutional distribution of legislative power. However, I think it will be enough for the purposes of your record to say simply that it is complicated.

As one illustration of how complicated it is, let me say this. I serve on the highest court of the Province of Ontario, a court that is the creature of provincial legislation and therefore a creature of the Province because it is created by a statute enacted by the Legislature of Ontario. Yet I am appointed to serve during good behavior until I am 75. I am appointed by the Federal executive

and paid by the Federal Government. That is just one illustration of how complicated the relationship between the two jurisdictions is.

Our government, both Federal and Provincial, is the British style parliamentary system with a monarch—thus, the name Royal Commission—and a Cabinet whose members are responsible to the legislature and its members.

Canada has a population of approximately 23 million. The Province of Ontario, which consists of about 10 or 11 percent of the country in area, has a population of approximately 8.5 million. Therefore, the population of Ontario is 36 percent, approximately, of the entire nation's population. In population, Ontario is Canada's largest Province.

My inquiry is provincial in scope. It relates only to Ontario. My mandate arises out of an order in council made by the Lieutenant Governor in Council of Ontario. That is to say that it is an executive order under the authority of a statute enacted by the Legislature of the Province of Ontario called the Public Inquiries Act. The order in council was made on December 21, 1977, but our public hearings did not begin until April 19 of last year. So we are just about a year old with respect to the hearings we have been conducting.

[The Executive orders follow:]



Executive Council

O.C. 3566/77

Copy of an Order-in-Council approved by His Honour the Administrator of the Government of the Province of Ontario, dated the 21st day of December, A.D. 1977.

The Committee of Council have had under consideration the report of the Honourable the Minister of Health, wherein he states that,

WHEREAS there has been considerable recent public discussion respecting the confidentiality of health and associated personal information.

The Honourable the Minister of Health therefore recommends that

1. pursuant to the provisions of The Public Inquiries Act, 1971, S.O. 1971, Chapter 49, the confidentiality of health and associated personal information, collected under legislation administered by the Minister of Health and any other relevant legislation administered by other Ministers of the Crown, be declared to be a matter of public concern, and that a Commission be issued appointing

THE HONOURABLE MR. JUSTICE HORACE KREVER, TORONTO to conduct an Inquiry with the following terms of reference:

- 1) to review all legislation administered by the Minister of Health (for example, The Public Hospitals Act, The Health Disciplines

Act, The Health Insurance Act and The Mental Act), together with any other relevant legislation administered by other Ministers, and any Regulations passed thereunder, to determine whether proper protection is given to the rights of persons who have received, or who may receive, health services, to preserve the confidentiality of information respecting them collected under that legislation;

- 2) to review the legality of the administrative processes under the above Acts; and
- 3) to report thereon to the Minister of Health with any recommendations for necessary amendments to the legislation and the Regulations passed thereunder;

2. All Government Ministries, boards, agencies and commissions be requested to assist the commission to the fullest extent in order that it may carry out its duties and functions;
3. The commission have the power and authority to engage counsel, expert technical advisors, investigators and other staff as it deems proper at rates of remuneration and reimbursement to be approved by the Management Board of Cabinet;

4. Part III of The Public Inquiries Act, 1971
be declared to apply to the said Inquiry and
to the commission.

The Committee of Council concur in the recommendation of the Honourable the Minister of Health and advise that the same be acted on.

Certified,

Deputy Clerk, Executive Council.



Executive Council

Copy of an Order-in-Council approved
by Her Honour the Lieutenant Governor, dated the
19th day of April, A. D. 1978.

The Committee of Council have had under
consideration the report of the Honourable the
Minister of Health, wherein he states that,

" WHEREAS, pursuant to Order-in-Council
numbered OC-3566/77 dated the 21st day of December,
A.D. 1977, a Commission was issued appointing the
Honourable Mr. Justice Horace Krever to conduct an
Inquiry respecting confidentiality of health
information;

AND WHEREAS questions have arisen as to the
scope of the Inquiry, so that it is desirable that
the terms of reference of the Commission be clarified;

The Honourable the Minister of Health
therefore recommends that

1. the said Order-in-Council numbered OC-3566/77
be amended by striking out the terms of reference
set out in Paragraph No. 1 thereof and sub-
stituting therefor the following:

- 1) to review all legislation administered by
the Minister of Health (for example, The
Public Hospitals Act, The Health Disciplines
Act, 1974, The Health Insurance Act, 1972

and The Mental Health Act), together with any other relevant legislation administered by other Ministers, and any Regulations passed thereunder, to determine whether proper protection is given to the rights of persons who have received, or who may receive, health services, to preserve the confidentiality of information respecting them collected under that legislation;

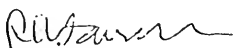
- 2) to review the legality of the administrative processes under the above Acts;
- 3) to investigate, inquire into and consider any misconduct, and any negligent or other improper activities, practices or conduct by any person, firm, corporation or organization in relation to the above Acts and Regulations and the administration thereof, including any non-compliance by any person, firm, corporation or organization with any of the above Acts and Regulations, and any activities, practices or other conduct by any person, firm, corporation or organization which coerced, induced, persuaded or otherwise prompted any such misconduct, negligence or other improper activity, practice or conduct, or which constituted an attempt or

an agreement to coerce, induce, persuade or otherwise prompt any such misconduct, negligence or other improper activity, practice or conduct; and

- 4) to report thereon to the Minister of Health with any recommendations for necessary amendments to the legislation and the Regulations passed thereunder.

The Committee of Council concur in the recommendation of the Honourable the Minister of Health and advise that the same be acted on.

Certified,



Deputy Clerk, Executive Council.

may per

Mr. KREVER. The origin of our inquiry is not easy to explain, but I think it is safe to say that it began with stories in the press about instances in which confidential health information had been given by persons obliged to keep the information confidential. The stories in the press led to questions in the legislature. When the answers to those questions were eventually forthcoming, they caused concern to be expressed by members of all parties in the legislature. Thus, the Cabinet decided to create an inquiry because it deemed the issue involved to be one of public concern.

At the time of the creation of the inquiry it was not known by those involved, either in asking the questions or in answering them, what the extent of the violations of confidentiality that occurred truly was. Indeed, it is probably fair to say that the area in which the greatest number of violations occurred, which is in the private casualty insurance sector, was not known by anyone. We came upon it, and perhaps the largest segment of our hearings was devoted to the practices in that area.

Although this is a gratuitous statement, I suspect that those practices occurred not only in Ontario but throughout North America because many, if not most, of the insurance carriers are related or in some cases subsidiaries of U.S. insurance companies.

We have a fair amount of information, Mr. Chairman. Rather than presume to know what would help you most, with that opening I will now sit back and await your questions.

Mr. PREYER. All right. Thank you, Mr. Justice Krever.

To bring out some of the facts which you have developed, we might ask a few general questions. Some of your most spectacular evidence related to the acquisition of medical records by private investigators through pretext calls. Could you describe for us how this practice was uncovered and how these investigators were able to obtain records through pretext calls?

Mr. KREVER. It was uncovered initially by a very summary and initial survey of the public hospitals in Ontario. The survey was concerned principally with the extent to which, if at all, police forces throughout the Province had attempted to obtain information from hospitals. The boards of hospitals are obliged to keep the information confidential and not produce it for the police except pursuant to subpoena.

In one small hospital in a small community near Niagara Falls there was a note kept by a medical record technician about a telephone call she had received. The note was simply a phone number. I will summarize this but I think it is accurate enough for our purposes here today. She said she had been called by a woman purporting to be a nurse in a large hospital in Toronto. The caller said that they had in the emergency department a woman who was very ill, that they knew the woman had been treated in the St. Catherine's Hospital, and they had to know how she had been treated.

The medical record technician was bright enough—or perhaps suspicious enough—to say, “Well, I will call you back.” She called for the file and then she looked up the phone number. She saw that the phone number she had did not match the phone number of the Toronto hospital.

She called back, and the name of that hospital was the Toronto General Hospital. There is also a Toronto East General Hospital. When the woman said this is not the Toronto General Hospital, the caller said, "Oh, I said Toronto East General Hospital." She then looked that number up and saw that it was not the number of that hospital either.

While she was engaged in this discussion, another telephone call was received in her office from a man purporting to be a physician in the emergency department, angry because this information was not forthcoming. He was unsuccessful.

With that phone number that she retained, we were able to locate a private investigation firm in Toronto. They had changed their phone number shortly after this incident, but we were able to get their identity by going back in the record. With that information Mr. Strosberg was able to interview one employee. That company in fact hired registered nurses, qualified registered nurses, to make these pretext calls. As a result of the information obtained from her, we had enough information to justify applying for a search warrant.

A search warrant was issued. We obtained files which disclosed that they were doing this on a rather wholesale basis. They were reporting to their clients who were insurance companies.

On the basis of that information we were able to get search warrants to obtain the records of those insurance companies. Those insurance companies then told us about other investigative reports they received from other private investigators. We then went to those private investigators whose files revealed other insurance companies. It went on in that fashion. That is how we obtained it.

The methods used by them varied. The pretexts varied. Sometimes they pretended to be a health-care worker. Sometimes they pretended to be conducting a neutral kind of survey, such as a shopping survey or accident survey. That would cause the respondent to open up and give information which would be used by the insurer against whom that individual might be making a claim.

Mr. PREYER. Did your investigation show that the pretext calls by private investigators were a widespread practice? Or was it a practice of just one isolated private investigator?

Mr. KREVER. It was very widespread. Mr. Strosberg could probably give you some statistics he was able to put together for the purpose of this attendance.

Mr. STROSBURG. We attempted to obtain specimen copies of investigative reports that were in possession of the insurance adjusters and insurance companies. We set up a rather simplified computer program. We did not attempt to obtain every report. We were trying to get specimen reports. We focused on the years 1976 and 1977, although there were some reports that went back as far as 10 years.

We processed 1,597 investigative reports from 32 investigative companies that represented 68 insurers or groups of insurance companies as principals and 41 independent adjusting companies. There were 157 separate hospitals contacted. You have to realize in Ontario there are 287 hospitals, so there were 157 hospitals contacted.

We segregated the hospitals by department. For example, there may be more than one contact at a hospital. There might be a contact at the medical records office, the business office, the emergency department, the physiotherapy department, or the X-ray department. The rates of success differed because in the medical records library there are professional people while in the business office there may not be.

There were 1,252 separate contacts at the 157 hospitals. The rate of success in obtaining medical information was 940 out of 1,252, which is about a 75-percent rate of success. We determined that there were 1,867 contacts with physicians in the Province, that is, physicians or physicians' employees in the physicians' offices. The information was obtained in 1,102 cases of the 1,867.

I think Mr. Justice Krever made it clear that he intended to determine the extent of the practice and not to stop until he rooted out each person who was involved. We got to 68 principals, at which time the insurance industry as a whole came forward to make an acknowledgment and admission as to what in fact had been the practice.

I will quote from the transcript of our hearings. This is a statement made by Mr. Wilson who is counsel to the Insurance Bureau of Canada. He said:

The Insurance Bureau of Canada represents in excess of 100 company groups and these company groups represent approximately 200 insurance companies which write 95 percent of the premiums in the Province of Ontario.

Mr. Commissioner: When you said "represent," I take it you mean that that is the number of companies who are members of the bureau?

The reply was, "Yes, that is correct." He goes on to say as follows:

The Insurance Bureau of Canada is a major organization of automobile, casualty, and property insurance companies transacting business in the whole Canadian market. Over 100 company groups are represented through the bureau. Collectively these companies wrote premiums in Canada in excess of \$4 billion in 1977, over 95 percent of the total general insurance premiums written by private insurance companies in Canada.

So certainly we had the body that represented the general insurance industry in Ontario and in Canada. On behalf of that bureau which represented those companies Mr. Wilson made the following statement:

The bureau wishes to make the following statement:

One, the insurance industry acknowledges that hospitals, hospital employees, doctors, and doctors' employees have an obligation to keep the contents of health records of patients confidential.

Two, generally members have in the past gathered through various sources medical information without the authorization of the patient.

Three, to determine the extent of the practice within the industry of obtaining medical information, the bureau offered to assist the Commission by conducting a survey which revealed that the total number of bodily injury claims in Ontario handled in 1977 was 115,019. The number of cases in which investigation reports were requested was 6,240. The best estimate of the number of investigation reports or internal memoranda prepared by company employees containing medical information obtained from hospitals and/or doctors' offices without the patients' consent was 420, representing 0.036 of 1 percent.

Four, the obtaining of such information has nothing to do with the maintenance of financial stability of the companies involved.

Five, such information was obtained to aid in the detection of and to prevent greatly exaggerated and fraudulent claims and for the establishment of adequate

claims reserves. Such claims are clearly against the public interest and, if paid, would increase the cost of insurance in Ontario.

Six, the bureau is not trying to justify actions contrary to current state of the law but would point out that such practices have not in any way prejudiced honest claims for the settlement of the claim.

Seven is an acknowledgment as to what steps they are taking to attempt to stop the practice.

In answer to your question, that statement makes it clear that it was an all pervasive practice throughout the industry in Ontario.

The investigation also showed that there were many lawyers who practiced in Ontario who either ordered such reports knowing that medical information was being obtained or received the reports in such volumes that they ought to have known that was what they were going to get.

We utilized this system. There had to be more than one occasion in which such a report was obtained. Lawyers were given notice. There were a number of lawyers to whom notice was given. They appeared, and I think there were in excess of 40 that were turned up in our random survey. These 40 appeared by counsel. Their counsel made a statement on their behalf which was:

Hospitals and their employees and doctors and their employees have an obligation to keep the contents of health records of patients confidential—

And that is what we called the principle of confidentiality—and that this was and is a subsisting and recognized principle. The solicitors represented knew, or ought to have known, that the principle subsisted and recognized and accepted same. For many years it has been a practice among the members of the legal profession and their staff engaged in personal injury litigation to instruct investigators and in consequence to receive investigation reports which would contain on occasion, amongst others, information from hospitals, hospital employees, doctors, and doctors' employees without the consent of the patient.

Therefore, these solicitors ought to have known that such instructions were likely to result in the receipt of investigation reports containing on occasion information from hospitals and hospitals, doctors and doctors' employees without the consent of the patient. Some solicitors on occasion specifically instructed investigators to attempt to obtain medical information from hospitals, hospital employees, doctors, and doctors' employees without authorization. These instructions under current state of the law cannot be justified.

It went on to recognize what the origins of the practice were. I am certain that Mr. Justice Krever put a question to Mr. Wilson, who acted on behalf of the Insurance Bureau. He wanted to know whether or not these lawyers that were before the Commission were the only lawyers in the Province who had carried on this practice. The Insurance Bureau was asked to canvass the insurance companies to canvass their lawyers to determine the extent of the practice.

Mr. Wilson, by letter dated November 9, 1978, said, amongst other things, "The practice referred to in the statement"—and that was the statement that I just read to you—"was generally followed throughout the Province by lawyers involved in insurance litigation."

Mr. KREVER. Mr. Chairman, I am not sure whether the answer Mr. Strosberg has given was completely responsive to your question. As I recall the question, when you asked about the pervasive nature of the practice, you referred to pretext methods.

Mr. PREYER. I first referred to pretext methods, but we are glad to get this information in other areas as well.

Mr. KREVER. Let me add to what has been given. It is quite clear that in many of the cases it was unnecessary to use pretext calls. The respondents, the prospective plaintiffs, or claimants gave information on being contacted sometimes without pretext. The health workers and institutions sometimes gave information without express pretext. By that I mean there was no false statement on its face but there was an assumption that the person calling was calling on behalf of their patient.

There is one other thing upon which I should comment. In the statement made on behalf of the Insurance Bureau of Canada one heard that it was the Bureau's belief that nobody whose privacy was invaded had been harmed thereby. Of course, that is a question of interpretation. A mere invasion of privacy may be interpreted as harm.

If you are interested, we have some specimen reports made by private investigators, a single private investigation firm, to its principal or principals. The gross invasion of privacy disclosed by these reports seemed to me to be harm itself.

These three that I have in my hand are not typical. We deliberately selected ones which were really gross.

Mr. PREYER. We would like very much if you would leave those with us and submit those for the record. That would be very useful.

[The material follows:]

MONDAY, JANUARY 24, 1977

The investigator received case instructions from our office in regards to this investigation.

TUESDAY, JANUARY 25, 1977

to

FRIDAY, JANUARY 28, 1977

During this time, the investigator made numerous discreet inquiries and subsequently disclosed that the Claimant's family doctor is B. H. Shroff whose office is located at 895 Bloor Street West, Mississauga, Ontario. Also that the Claimants had been treated by Dr. D. G. Lowe whose office is located at 1221 Bloor Street West, Mississauga, Ontario.

During this time, the investigator also disclosed that both Claimants had been receiving treatment at the Mississauga and Mt. Sinai Hospitals.

During the discreet inquiries, the investigator disclosed that Claimant No. 2's date of birth is May 1st, 1946 and his place of employment as being at the International Time Recorder.

MONDAY, JANUARY 31, 1977

to

FRIDAY, FEBRUARY 25, 1977

During this time, the investigator made numerous discreet inquiries and subsequently disclosed from the St. Joseph's

Hospital Medical Records Department that both Claimants had been treated within their emergency department several years ago but the specific dates or reasons were not noted.

The investigator was advised that in order to obtain the information from the files within the emergency department, the specific dates would have to be obtained.

The investigator discreetly contacted Dr. B. H. Shrott's office.

The investigator was advised that both Claimants had seen the doctor in regards to a motor vehicle accident quite a few months ago. The investigator was advised that when the doctor had seen both Claimants they were attending the Mississauga General Hospital for physiotherapy for back problems.

The investigator was advised that Claimant No. 1 was treated with 282 meps and Claimant No. 2 was treated with heat, rest, ASA's, lumbar spine and 282 meps.

The investigator made further discreet inquiries but was advised that the Claimants had not been seen by the doctor since that time.

The investigator subsequently contacted Dr. D. G. Lowe who is the Claimants family physician.

The investigator discreetly disclosed from the doctor the following information relating to both of the Claimants.

[REDACTED] were in an automobile accident about a year and a half ago and he hasn't as yet worked from this accident and he complains of a chronic low back pain and ... actually that's a lie, he is finally back to work. He complains of low back pain, but he ascribes most of his low back pain to the time that he went over the handlebars of his bicycle and landed on his back.' But since this accident, he had a lot of low back pain and he was working as a District Sunday Sun Paper Boy, for awhile, and he was on Welfare. He was on Welfare for about a year and a half. He just recently, apparently gone into a business with a friend of his, restoring cars.

Now, [REDACTED] has got a long, long standing psychiatric history. She's been in the Mississauga Hospital innumerable times and she's been under Dr. Porter and she's been under other doctors. She rather unfortunately got hooked up with me a while back. There is a long standing social problem. They live in absolute squalor. They're dirty. He's an obese, just God-awful looking guy and she is always complaining about their sex life and I can imagine why. As I said, she has been depressed. She's made suicidal gestures. She cut her stomach the last time and ended up in Hospital. They have homemakers in there, all the time, and apparently it's just absolute squalor. I have never seen their house.

I've been basically in the role of supportive with respect to their psycho-social problems.

I was treating the back for awhile. I had sent him, just because it was an automobile accident, he had normal X-rays and so on, of his back, but I sent him to see Geoff French, who is an

Othopod, out here, and he agreed that it was just 'a chronic fibrocytis' and there was nothing to do and it would settle down. So, I got that out of the way.

This Dr. French had also sent [REDACTED] to a Urologist, because she is chronically dribbling and wetting her pants.

So you see, I don't get too involved because with these kind of people, I get fed up with them because they are flitting around from here, there and everywhere. I never know what's going on. I find that I don't give them particularly great care, although I was talking and spending a lot of time with her about a month ago. But I have not seen her for about three weeks. "

The investigator subsequently contacted Dr. G. R. French's office, who is an Orthopedic Surgeon. The investigator discreetly disclosed from the doctor's secretary that Claimant No. 2 had been referred to the doctor in regards to traction injury to his lumbar spine.

She related that the X-rays of the Claimants' lumbar spine had been taken at the Mississauga Hospital on October 26th, 1976 and revealed the following:- 'There is a borderline narrowing at L4-5. No other significant findings.'

The investigator was advised that Claimant No. 2 first saw Dr. French on December 9th, 1976 at which time the doctor diagnosed the problem as 'low back strain'.

The doctor subsequently prescribed the Claimant's treatment in him continuing with the physiotherapy consisting of hot packs, flexion exercises. Also the Claimant was given a prescription for a camp corsette which he was to wear for three months.

The investigator was advised that the Claimant could take some mild over-the-counter medication for pain.

The investigator was also advised that the doctor noted that there was no indication for surgical intervention.

The investigator made further discreet inquiries and subsequently contacted Dr. C. Knowlton's office who is a surgeon.

The investigator was discreetly advised from the doctors' secretary that he has not seen Claimant No. 2 for at least ten years.

The investigator was advised that Claimant No. 2's father was a very good friend of the doctors' and also that Claimant No. 2's father had recently died of Carcinoma of the lungs.

The investigator made further discreet inquiries and was advised by the doctor that Claimant No. 2 was a tremendous problem to his father and also that Claimant No. 2 was an adopted child.

The doctor advised the investigator that he had not seen the Claimant No. 2 for such a long time, he doesn't really know what his problems are at the present time.

The investigator also made discreet inquiries in regards to Claimant No. 1 at which time Dr. Knowlton related that the last time he seen Claimant No. 1 was during 1972. He advised the investigator that he is a plastic surgeon and the only reason he saw Claimant No. 1 was for an abdominal scar.

He related that that was the only time he saw the Claimant.

The investigator subsequently contacted the Mt. Sinai Hospitals' Medical Records Department and through discreet inquiries, disclosed that Claimant No. 1 was first examined within their emergency department on January 16th, 1977 at which time she was diagnosed as having a urinary tract infection. There was a notation within her medical file "patient refused to take prescription."

The investigator was also advised that Claimant No. 1 was next seen within their emergency department on January 20th, 1977 for a cystoscopy, during which time the swab of the cervix was done and also a CBC (complete blood count) and chemistry.

The investigator was advised that there was no summary noted within her records.

The investigator subsequently contacted Dr. J. Porter's office who is a psychiatrist. The investigator discreetly disclosed that Claimant No. 1 is a patient of the doctors. The investigator was advised that no information could be released without proper written authority.

The investigator subsequently contacted the Mississauga General Hospital medical records department but was unable to disclose any information relating to either Claimant without proper written authority.

The investigator made further discreet inquiries and subsequently disclosed that Claimant No. 1 was believed to have been treated at the St. Joseph's Hospital approximately five and a half years ago for a kick in the pelvis. Also that Claimant No. 2 is believed to have been treated in St. Joseph's Hospital approximately six years ago for a motorcycle accident.

The investigator made further discreet inquiries but was unable to disclose any further information to assist this investigation.

MONDAY, JANUARY 24, 1977

The investigator received case instructions from our office in regards to this investigation.

TUESDAY, JANUARY 25, 1977 to TUESDAY, FEBRUARY 15, 1977

During this time, the investigator made numerous discreet inquiries in relation to the Claimant's medical background and contacted the office of Dr. R. F. Patterson, a General Practitioner, and was informed that Dr. Patterson first saw the Claimant approximately two to three years ago. The Claimant has juvenile rheumatoid arthritis very severe.

The investigator was informed that the Claimant has rheumatoid arthritis in every joint in her body. She is on myochrysine lcc every week. Her blood is checked every two weeks. She's on prednisone 5 mg. twice daily and codeine phosphate 60 mg. four times a day; naprosym 250 mg. twice a day.

She was involved in a motor vehicle accident in November of 1975. She was struck from behind. She had a whiplash to her neck. She suffered quite considerably with that as she was pregnant at the time because we had to stop all the treatments because of the fetus. She had a exacerbation of the arthritis and her neck was hurting her like hell and the pregnancy threat was very uncomfortable for her. The accident aggravated her arthritic condition.

Dr. Patterson last saw the Claimant on January 14, 1977. She had no complaints at that time. She was just in for her weekly dose of myochrysine.

The investigator, unable to disclose any further information from the office of Dr. Patterson, contacted the office of Dr. T. Topp, an Arthritic Specialist, and was informed that Dr. Topp has been treating the Claimant off and on for years; approximately five to ten years.

She has got very, very severe rheumatoid arthritis which goes right back to childhood - since age 2. She is in her 20's now and she seems to be getting around to see various people. She is on multiple drugs for her arthritis including imuran. She's had one total hip arthroplasty.

The doctor states that she has a long history of treatment and has general rheumatoid arthritis involving multiple joints. Dr. Topp stated that he has not seen the Claimant for approximately six months.

The investigator, unable to disclose any further information from the office of Dr. Topp, contacted the office of Dr. T. Barrington, an Orthopedic Surgeon who stated that he has no file on the Claimant.

The investigator then contacted the medical records department of Sunnybrook Hospital and was informed that:-

- " The patient has had three admissions to our Hospital all for the same diagnosis, rheumatoid arthritis. The first admission she was discharged in December of 1973. The second admission was the end of 1974 and the last admission was in October of 1976. For all three admissions, she was under the care of Dr. J. Topp.

Dr. Topp's discharge summary dated October 27th, 1976 written on the patient's last admission reads as follows:- "This 25-year-old girl was admitted for reassessment. She first developed arthritis at the age of two. This affected her right knee and she had problems with both knees and both ankles until about the age of twelve. Biopsies were carried out and definitive diagnosis was not made and at one point she received full chemotherapy for TB. She was in and out of a wheelchair over this period of time. Still's disease was diagnosed eventually and her disease settled in her teens.

From about the age of 12 to 19, she was able to walk, play tennis and field hockey. Her only problem being occasionally mild discomfort and swelling of her knees.

At 19 her disease spread and involved her hips, elbows, wrists, MP joints, PIP joints and knees and ankles. Over the past five years, these joints have become increasingly more involved with exacerbations from time to time.

Two years ago, she had a left hip prosthesis inserted. One year ago, she became pregnant and her gold and chloroquin were discontinued. She delivered a normal child three months ago and at that time, her gold and chloroquin therapy were recommended. By this time, her arthritis had flared up and her functional status on admission was that she could only walk half a block with discomfort and pain in the right ankle and she was having extreme difficulty using her right arm which was very weak. She experienced a lot of pain in her right wrist and in the MP joints and PIP joints of the right hand. She is experiencing morning stiffness until about 2:00 p.m.

On admission, she was taking Prednisone 5 mg. BID; Chloroquin 250 mg. OD; gold once weekly; Entrophen 1.2 grams QID; Codeine 60 mg. in the morning. There were no other relevant symptoms on admission.

Investigations: Urinalysis - negative. Hemoglobin 10 grams; Hematocrit 30.7 ESR-45; WBC 10,700; 70% polymorphs - hypochromic microcytic picture; 610,000 platelets.

BUN 16; serum creatine 0.6; serum electrolytes normal; serum proteins - total 7.5; serum albumin - 3.3; alpha 1 globulin - 0.4; alpha - 20/9; beta 1.1; gamma 1.8; serum iron 40 mg./ 100 ml.; TIBC - 345; latex negative; ANF negative; salicylate level - 21. Chest X-ray negative; X-rays of knees, elbows negative. X-ray of hip demonstrates Charnley-type arthroplasty with otherwise normal features although tomograms had to be taken to exclude pelvic fracture.

X-rays of hands demonstrated extensive loss of cartilage in the right radial carpal and intra carpal joints with destructive changes involving the carpal bones and loss in volume of the carpus in general. There was also loss of cartilage in the right 3rd, 4th and left 4th MP joints with destruction of subchondral bone.

X-ray of feet demonstrated loss of cartilage in the right 1st MP joint with hallus valgus.

Course and Treatment: The patient was treated with physiotherapy and rest.

Naprosyn in a dose of 250 mg. TID, was added to her therapeutic regime. Intra-articular steroids were injected into the active ankle, the right wrist, the two afflicted MP joints and the three inflamed PIP joints. The grip was only 20 on admission had improved to 80 by the time of discharge.

Ophthalmologic consultation was obtained. Myopia was noted.

There were no toxic effects from the Chloroquin therapy. Iron therapy was instituted on account of a low serum iron. The patient was considerably improved at the time of discharge and the function in the right arm was much better.

Discharge Medications: Myochrysine 50 mg. weekly
 Chloroquin 250 mg. OD daily at night
 Prednisone 5 mg. BID
 Entrophen 325 mg. 1/4 tabs QID
 Naprosyn 250 mg. TID
 Ferrous Gluconate 300 mg. TID
 Codeine 60 mg. in am. p.r.n.

The investigator, unable to disclose any further information from the Scarborough General Hospital, contacted the Toronto East General Hospital's medical records department and was informed:

" Patient hospitalized in January of 1971 for an incomplete abortion under Dr. J. Moffatt. A D&C was done during this hospitalization. Hospitalized in July of 1972 with diagnosis of rheumatoid arthritis; therapeutic abortion; fibro-adenoma of breast under Dr. Moffatt. The fibroadenoma of the breast was excised.

Hospitalized in May of 1973 for rheumatoid arthritis under Dr. J. Topp.

Hospitalized in September of 1973 for rheumatoid arthritis and secondary degenerative arthritis left hip. A left total hip replacement was done by Dr. T. Barrington.

Hospitalized in 1974 for a therapeutic abortion, under the care of Dr. Moffatt. "

The investigator then contacted the Etobicoke General Hospital, medical records department and was informed that no information could be obtained without written authorization.

The investigator, unable to disclose any further information in regards to the Claimant's medical background, subsequently made discreet inquiries in regards to the Claimant's financial background and was informed that the Claimant is married to [REDACTED] No employment is listed for either.

The Claimant came on file in January of 1976 with a chattel mortgage registered with GMAC in Toronto for the amount of \$5,532.00 which expires in December of 1978.

In January of 1977, it shows another chattel mortgage registered with the Canadian Imperial Bank of Commerce for the amount of \$4,153.00 which expires in December of 1979.

The investigator was unable to disclose any further trade nor derogatory reports in regards to the Claimant.

The investigator, after numerous attempts, subsequently contacted the Claimant's place of employment Rocchettis Wigtown in Barrie, Ontario and was informed by the Manager that the Claimant had been working for her for a few days in a part-time position for the last

week selling wigs.

The investigator was informed that the Claimant had previously worked for the company in Toronto and had left to have a child.

The investigator subsequently made numerous inquiries at Rocchettis Wigtown in Toronto, Ontario but at this time has been unable to obtain any information in regards to the Claimant.

The investigator subsequently discontinued to complete reports.

FRIDAY, NOVEMBER 25, 1977

The investigator received case instructions from our office in regards to this investigation.

SATURDAY, NOVEMBER 26, 1977 to THURSDAY, DECEMBER 8, 1977

During this time, the investigator made periodical observations and enquiries at the Claimant's place of residence, located at [REDACTED], which is described as a two-storey, grey brick residence with white and black trim and attached two-car garage.

During this time, the investigator was unable to observe the Claimant or any activities.

During this time the investigator made discreet enquiries with the Claimant's neighbours. The investigator was unable to receive an answer from [REDACTED]. At [REDACTED], the investigator was informed that these people did not know the Claimant. At [REDACTED], there was no answer at this residence. At [REDACTED], the investigator spoke with a Mrs. [REDACTED] who stated that she was the Claimant's next door neighbour, but that she did not know the Claimant well. She stated that the family was quiet and that she very rarely saw anyone around the house and very rarely spoke to the Claimant.

The investigator proceeded to [REDACTED] and spoke with a Mr. [REDACTED] who advised that the Claimant and her family had been living at this address for approximately three years and that he had known them since they had moved to the area. He stated that they are a quiet family and keep mainly to themselves. He stated that the Claimant and her husband usually come over each year for a drink at Christmas, but that is the only time that the [REDACTED] have done any socializing

with the [REDACTED]. He stated that he does not think the couple is active socially. He further stated that he had seen the Claimant out in the yard several times during the summer, doing some gardening.

The investigator then proceeded to [REDACTED] and spoke to a Mrs. [REDACTED] who stated that she did not know the Claimant. The investigator attended [REDACTED] and [REDACTED] and was also informed that these people did not know the Claimant. The investigator received no answer from [REDACTED], [REDACTED] and [REDACTED].

The investigator, through his sources, disclosed that the Claimant's date of birth is November 8, 1938 and that the Claimant was employed at Lorne Park Community Centre, as a part-time teacher from 10:00 a.m. to 12 noon each day, where she has been employed for three years at the rate of \$7.50 per hour.

The investigator was unable to disclose any further information at this time in relation to the Claimant or her social activities.

FRIDAY, DECEMBER 9, 1977

The investigator again proceeded to the Claimant's place of residence and set up re observations. After approximately an hour and a half, the investigator observed the Claimant, who was not wearing any collar, brace or visible support and is described as female, white, approximately 39 years of age, approximately 5 ft. 6 inches in height, weighing approximately 145 lbs., with black hair, wearing an orange coat, woolen hat, mauve slacks, gloves and boots, to exit from the front door of the residence while extending her right arm and hand to open and close the door. The Claimant was observed to bend slightly forward from the waist, to extend both her arms and hands to lift a snow shovel, which was leaning against the side of the garage. The Claimant, while carrying the snow shovel with both her arms and hands extended at waist level, was observed to walk

in apparent normal manner, while turning her head and neck from left to right, while observing her surroundings and to proceed to the end of the driveway, where she was observed to bend forward from the waist, and while holding the shovel in both hands, to proceed to shovel the snow from the driveway. The Claimant was observed to push the shovel, while bending from the waist forward, extending both her arms and hands and to lift the shovel full of snow from the driveway and to dump it over the south side of the driveway. The Claimant was observed to repeat this motion while cleaning the driveway. After approximately five minutes, the investigator observed an orange coloured van with the name G. M. SERVICE CLEANING on the side to stop at the end of the Claimant's driveway, at which time the Claimant engaged in a conversation with two young males within the van. The two males, approximately 20 years of age, then parked the van in the driveway next door to the Claimant's residence and exited from the van while carrying snow shovels. The Claimant then was observed to lift her snow shovel, with both her arms and hands extended and to carry the snow shovel in her right hand and to walk the length of the driveway and to place the snow shovel next to the garage and to extend her left arm and hand to open the residence door and to enter.

The investigator observed the two males to complete shovelling the snow from the driveway, and then to depart from the residence in their van. The investigator, observing no further sign of the Claimant or any activities, discontinued observations.

During the investigator's observations, the Claimant was observed bending from the waist forward, using both her arms and hands, turning her head, shoulders and body from left to right, bending her head and neck in an upward and downward motion, and walking about in apparent normal manner.

During the investigator's observations, the Claimant showed no signs of pain, physical discomfort or restrictions. The investigator subsequently discontinued and proceeded to complete reports.

SATURDAY, DECEMBER 10, 1977 to THURSDAY, DECEMBER 15, 1977

During this time, the investigator again made periodical observations at the Claimant's place of residence, but was unable to observe the Claimant or any further activity.

During this time, the investigator made numerous discreet enquiries in relation to the Claimant's medical background, in an attempt to disclose up-dated information and, through a confidential source, disclosed the following information.

From the office of Dr. A. I. MARGULIES, Psychiatrist, located at 123 Edward Street, Toronto, Ontario, the investigator was informed that the Claimant was last seen on June 7th, 1976.

From the office of Dr. MILO TYNDEL, Psychiatrist, 40 Wellesley Street, Toronto, Ontario, the investigator was informed that the Claimant was last seen on November 8th, 1973.

From the office of Dr. H. SCHUTZ, a Neurosurgeon, located at 3025 Hurontario Street, Mississauga, Ontario, the investigator was informed that the Claimant was last seen on March 13th, 1974.

From the office of Dr. E. W. HOWES, Orthopaedic Surgeon, 40 Wellesley Street, Toronto, Ontario, the investigator was informed that the Claimant was seen February 12th, 1974 and last seen November 6th, 1974.

From the office of Dr. C. M. KINCAIDE, General Practitioner, 43 Wellesley Street, Toronto, Ontario, the investigator was informed that the Claimant had one visit only on February 6th, 1974.

From the office of Dr. S.S. YOUNG, Dental Surgeon, located at 2490 Winthrop Crescent, Clarkson, Ontario, the investigator was informed that the Claimant

had one visit only, on April 25th, 1973.

From the office of Dr. GLEN MacDONALD, Orthopaedic Surgeon, Dundas Street, Toronto, Ontario, the investigator was informed that the Claimant had only one visit, on May 6th, 1976.

From the office of Dr. JEAN PORTER, a Psychiatrist, located at 111A Dundas Street East, Mississauga, Ontario, the investigator was informed that the Claimant had one visit only on a medical-legal report.

From the office of Dr. B. S. SEHMI, an Orthopaedic Surgeon, located at 559 College Street, Toronto, Ontario, the investigator was informed that the Claimant had two visits only - on June 7th, 1973 and on March 17th, 1973.

From the office of Dr. J. McHATTIE, Gastro and Internal Medicine at Toronto General Hospital, 101 College Street, Toronto, Ontario, the investigator was informed that the Claimant had one visit only on November 4th, 1974.

From the office of Dr. K. J. MacRITCHIE, a Psychiatrist at Toronto General Hospital, the investigator was informed that the Claimant was seen only once - no date was available.

From the office of Dr. F. H. PROUSE, Orthopaedic Surgeon, 21 Queensway, Toronto, Ontario, the investigator was informed that the Claimant was seen on May 16th, 1973, June 5th, 1973 and May 8th, 1974.

From the office of Dr. J. G. D. ANDERSON, 2140 Bloor Street West, Toronto, Ontario, the investigator was informed that the Claimant was seen only once, on April 22nd, 1976.

The investigator also contacted the office of Dr. MICHAEL GITTERMAN,

General Practitioner, 1221 Bloor Street East, Mississauga, Ontario, and was informed that the Claimant was last seen on June 19th, 1974, and that the Claimant's family also attended Dr. GITTERMAN. There was no up-date information on the Claimant's chart.

The investigator also contacted Dr. JOHN HARKINS, Obstetrician and Gynecologist, Toronto General Hospital.

From all these doctors, the investigator was informed that there was very little up-date information in relation to the Claimant and that the Client already has most of the information available, and that from the majority of the doctors, no information was available without written authorization.

The investigator, through discreet enquiries, disclosed that the Claimant had also attended the office of Dr. THOMAS S. C. HO, who is now her family doctor, located at 120 Lakeshore Road West, Port Credit, Ontario.

The investigator, through a confidential source, disclosed the following information from the office of Dr. THOMAS S.C. HO.

The investigator was informed that the Claimant was last seen by Dr. HO on March 14th, 1977. The investigator was informed of a report in the Claimant's chart, which reads as follows:

"May 25, 1976 - Dr. DOUGLAS J. GARE - D & C performed. I gathered during the interview in the office that the patient and her husband are not getting along well and also the patient seems depressed and irritable. I confronted her with this and she denied these facts and still insisted that she wanted her tubes tied. She also wants me to look around for another pathology because she insists that her abdominal and pelvic pain are not psychogenic."

The investigator was informed that Dr. HO saw the Claimant on the following dates:

October 27th, 1976 - Left lower abdominal pain with frequent burping.

December 2nd, 1976 - Still has pain in right and lateral lower quadrant - feeling of pressure, but otherwise soft. Had a colonoscopy. Pain started after attending a lecture by someone at McMaster who stated that a hernia could be caused by a colonoscopy.

January 12, 1977 - Pain in right lower quadrant around the opening of the inguinal canal region. No hernia seen.

January 20, 1977 - Not much improvement.

March 9, 1977 - Depressed, but does not want to relate. Called Dr. JEAN PORTER, Psychiatrist.

March 14, 1977 - Depressed - seen in hospital in Psychiatry overnight.
Last visit.

Dr. HO saw Claimant's husband on the following dates:

September 7, 1977 - family problems gradually solving themselves.

November 9, 1977 - Claimant's husband was last seen by Dr. HO - Family problems better, but not yet solved.

The investigator was informed of a report, dated February, 1977 from Dr. GITTERMAN, the Claimant's former family physician. This was her last visit to DR. GITTERMAN and she switched over completely to Dr. HO.

The report reads as follows:

"Saw the children only a few times - [REDACTED] and [REDACTED]"

The investigator was informed that the Claimant was recently hospitalized March 13th, 1977 in the Mississauga Hospital. She was admitted under Dr. JEAN PORTER, Psychiatrist and the following report was given by Dr. PORTER:

"Diagnosis of borderline schizophrenic. Admitted March 13th, 1977. In hospital two days prior, but insisted on leaving. She was confused and depressed over a few months about her marriage and her role as wife or mother, or in a career. She denied any possibility of emotional illness and had resisted any psychiatric treatment in 1974. She had a psychological testing done in 1974 which read as follows:

'showed a significant elevation of the MMP-1, hypochondriasis, depression and hysteria. Evidence of suspiciousness, distress and brooding and resentment over real and imagined wrongs. The Rorschach Test (Inkspots) also suggested an obsessive, compulsive feature, attention to small insignificant details. She would prefer an assertive role in life, but feels that such a role is unattainable in life for her and consequently has periods of tensions and frustrations. The TAT test would suggest that she has some sexual dysfunction with marital discord. She was given anti-depressants."

Dr. PORTER's note continues - "Past history - Born in New Jersey - father killed in drowning accident when she was 8 years old. Financial problems after this and legal problems within the family. Mother remarried once and is about to remarry again. Stepfather died five years ago. Has two older sisters; younger brother committed suicide a few years ago - sounds as if he suffered from a schizophrenic disorder. She married her husband when she was 18. Lived in New York and Boston and moved to Mississauga eight years ago. Went to University for four years and received a B.A. Trained to be a teacher and worked as an airline stewardess. She married because she was pregnant and has always felt that she did not make the decision about the person she was going to marry. She felt more strongly about her previous boy friend and her mother had broken up this relationship. Recently, this person had contacted her and she had met him, but she was disappointed as he was not the wonderful person she had pictured over the years.

Examination showed a pleasant, attractive woman with dark brown wavy hair, with a medium stature. She was very unsure of herself, shaking and depressed and had occasional thoughts of suicide. Very suspicious, but bearing no specific thought disorder. Her thinking is often vague and not goal oriented. Felt that she suffers from borderline schizophrenic illness with the features of neurotic anxiety and depression, but the paranoid element and the difficulty with thinking under stress places her in the category of borderline schizophrenic. She was involved in individual group therapy and was seen weekly by myself."

The investigator made further enquiries, but was unable to disclose any further doctors that may have treated the Claimant recently.

The investigator was also informed from Dr. HO's office that there were no letters or notations regarding any physical problems since 1974, with the exception of her abdominal pain.

The investigator, unable to disclose any further information in relation to the Claimant's medical background, discontinued to complete reports.

Mr. PREYER. Mr. Strosberg, you mentioned a figure of 420 contacts which the Insurance Bureau admitted. They indicated that was a very small percentage of all claims involved. Do you have any judgment on how accurate their figure of 420 contacts was? Do you accept that as being accurate?

Mr. STROSBURG. The only thing I can say is what I have already said. It was the number of files that were processed by the Commission. It also has to be taken in light of a number of cases that eventually get to the litigation stage. That is where there is enough money involved to justify the retention of an investigator in the first instance. It is very difficult to really put those statistics into perspective because of those factors.

Mr. KREVER. May I return to what I said a minute ago about the statement that no harm occurred? I do not say that it is necessarily the majority of cases but in some of the cases in which private investigators were retained to obtain health information about prospective claimants it is clear from the answers given by the private investigators that their perception of their client's need was this: If they got some adverse information, even though not relevant for the purposes of this claim—adverse background history such as very personal information relating to sexual activity, abortion, and so—then they thought this would be very helpful to their principals, their insurers. This was because of their belief that it might strengthen their bargaining position when it came to out-of-court settlement negotiations. They thought the claimant would not want to go to court if this kind of information might be brought up.

Mr. PREYER. Let me ask one more question and then I will give Mr. Kostmayer a chance to question. He has been very patient.

You mentioned obtaining of these records by pretext. You talked about the role of lawyers and insurance adjusters. What have you found out about the ability of insurance adjusters to obtain this information from doctors? Have doctors been observing the confidentiality of patient records? Have they been giving up the information as easily as you indicate some other health people have?

Mr. KREVER. Most of the attempts to obtain information from physicians were attempts to obtain it from their employees. It is fair to say that the vast majority of information that came from doctors' offices came from nonprofessional employees, not a nurse working in a doctor's office but a receptionist clerk.

It can be argued that a physician has a professional obligation to instruct his employees or her employees about his or her obligation to insure that the employees do not do what the physician himself or herself ought not do.

Do you agree with that, Mr. Strosberg?

Mr. STROSBURG. Yes, I do. It seemed that the investigators were exploiting the probably natural attempt of one physician's office to aid another. A call would be purporting to be from a specialist's office. They would say they were going to see this patient and ask for the background information to make it easier for the doctor when he examines the patient. It was that type of pretext that was being used. It was that exploitation of the natural tendency of someone in a physician's office to attempt to cooperate with a

colleague that caused the information to be released in many situations.

Mr. KREVER. The most surprising story was that of a physician, and our inquiry really began with his experiences. He was an employee of the Provincial Government in the Ontario Health Insurance Plan. For a considerable period of time he had gone out on behalf of an insurer and obtained information by going directly to patients in the hospital. In some cases he donned a lab coat and appeared to be a staff member of that hospital. In none of the cases in which he did this did he have medical privileges or physician privileges in the hospitals. His story was the most surprising one we encountered.

Mr. STROSBERG. There was one very surprising situation. He did just what was described. He examined a paraplegic who was in the hospital who really had no idea that this fellow poking around was not on the staff.

Mr. PREYER. Mr. Kostmayer?

Mr. KOSTMAYER. Thank you very much, Mr. Chairman.

Mr. Justice Krever, let me join with Congressman Preyer in welcoming you and Mr. Strosberg here. Thank you for giving us so much of your time so far away from your home country.

I wonder if for the record you can once more characterize for me in your own opinion the conduct of these insurance companies in Canada in the gathering of this information. Did you regard it as illegal or informally illegal? Could you characterize for me in your own words what you generally regarded as their conduct?

Mr. KREVER. I could answer you by referring to their concession. As indicated before, I ought not express my own opinion before reporting. However, it is quite clear from their own concession and the public statements that their actions were not defensible when one took into consideration the sources from which the information was obtained.

The information was in the hands of people obliged or institutions obliged by law to keep the information confidential. In the knowledge that was so or in many cases where they ought to have known that was so, nevertheless, they went to these people and institutions and obtained information.

One could form a legal opinion as to the characterization of conduct which amounts to agreement by two or more persons to cause another person to breach the law. However, I do not think that I am in any better position than anybody else to form that opinion.

Mr. KOSTMAYER. There was actually violation of Canadian law that occurred?

Mr. KREVER. There were violations, not necessarily of Canadian law, but of Provincial law by persons who gave out information without their patients' consent, notwithstanding the existence of a statutory prohibition against that.

Mr. KOSTMAYER. Have there been any indictments of those who have improperly obtained medical files or is this currently a national crime? Are there any civil penalties?

Mr. KREVER. Most of it will arise in the context of disciplinary activity by the various disciplinary bodies, professional and institutional.

This matter is under appeal, but one of the investigative firms subsequently had proceedings brought against it. I think only last week its license was cancelled.

Mr. STROSBERG. I think you should appreciate it is not just the obtaining of health information from physicians and hospitals and their employees, but there were situations where health information was obtained from schools, employers, and a whole host of persons and institutions.

Mr. KOSTMAYER. Often under false pretenses?

Mr. STROSBERG. On some occasions, yes. There were these people and institutions that also had an obligation to keep the information confidential. It was not just the hospitals and physicians. There was the Provincial health insurance plan that was on occasion approached and information was obtained from that plan also.

Mr. KOSTMAYER. Did you find that these insurance companies in your own country had American affiliates or were American owned in some cases? If so, to how great an extent?

Mr. KREVER. I have a list of the member companies and groups of the Insurance Bureau of Canada. Many of them are subsidiaries of foreign companies, but those foreign countries include not only the United States but Great Britain as well.

Mr. KOSTMAYER. Is it pretty evenly distributed among a number of countries?

Mr. STROSBERG. Most of the major insurers in Canada carry on business in the United States.

Mr. KOSTMAYER. Are they American owned?

Mr. STROSBERG. Yes, I think some of them are.

Mr. KOSTMAYER. Do you have a list there for the subcommittee of these companies?

Mr. PREYER. Without objection, that will be received for the record.

[The material follows:]

Member Companies and Groups Insurance Bureau of Canada

Abstainers' Insurance Company
 Aetna Casualty & Surety Company
 Aetna Casualty Company of Canada
 American Bankers Insurance Company of Florida
 American Mutual Liability Insurance Company
 American Reinsurance Company
 Anglo-Canada General Insurance Company
 Gibraltar General Insurance Company
 Argonaut Insurance Company
 Atlantic Insurance Company Limited
 Aviation and General Insurance Company Limited
 Cabot Insurance Company Limited
 Canada West Insurance Company
 Canadian General Group
 Canadian General Insurance Company
 Toronto General Insurance Company
 Traders General Insurance Company
 Canadian Home Group
 Adriatic Insurance Company
 Canadian Home Assurance Company
 Canadian Indemnity Company
 (Les Prévoyants du Canada)
 The Canadian Provident General Insurance
 The Personal Insurance Company of Canada
 Canadian Reinsurance Company
 The Canadian Surety Company
 Edmonton Canadian Insurance Company
 Olympic Insurance Company
 Transamerica Insurance Company
 Canadian Universal Insurance Company Limited
 Chateau Insurance Company
 The Citadel General Assurance Company
 (Commerce Group)
 Le Groupe Commerce Compagnie d'assurances
 Commercial Union Assurance Company of Canada
 Canada Accident & Fire Assurance Company
 Stanstead & Sherbrooke Insurance Company
 The Continental Insurance Company
 The Dominion Insurance Corporation
 Niagara Fire Insurance Company
 Royal General Insurance Company of Canada
 The Tokio Marine & Fire Insurance Company Limited
 The Co-operators Group
 Co-operative Fire & Casualty Company (CIS, Regina)
 Co-operators Insurance Association (CIAG, Guelph)
 (Independent Ins. Managers Ltd.)
 Cornhill Insurance Company Limited
 The Canadian Commerce Insurance Company
 The Canadian Provincial Insurance Company
 Provincial Insurance Company Limited
 The Unity Fire & General Insurance Company
 Cumis Insurance Society, Incorporated
 Dominion of Canada Group
 Casualty Company of Canada
 Dominion of Canada General Insurance Company
 Eaton/Bay Insurance Company
 Economical Mutual Insurance Company
 Missisquoi & Rouville Insurance Company
 Perth Insurance Company
 (Employers of Wausau)
 Employers Mutual Liability Ins. Co. of Wisconsin
 Employers Reinsurance Corporation
 English and American Insurance Company Limited
 Equitable Group
 Equitable General Insurance Company
 Industrial General Insurance Company

(Chubb & Son Inc.)
 Federal Insurance Company
 South British Insurance Company
 Federated Mutual Insurance Company
 Federation Insurance Company of Canada
 Helvetia Swiss Fire Insurance Company Limited
 Switzerland General Insurance Company Limited
 (Shaw & Begg Limited)
 Fireman's Fund Insurance Company of Canada
 Foremost Insurance Company
 Foresters Indemnity Company
 The General Accident Assurance Company of Canada
 Canadian Pioneer Insurance Company
 Scottish Canadian Assurance Corporation
 General Reinsurance Corporation
 General Security Insurance Company of Canada
 La Société d'Assurance des Caisses Populaires
 Gerling Global General Insurance Company
 Gerling Global Reinsurance Company
 Gore Mutual Insurance Company
 Grain Insurance & Guarantee Company
 Great American Group
 American National Fire Insurance Company
 Great American Insurance Company
 The Great Lakes Reinsurance Company
 Guarantee Company of North America
 Guardian Insurance Company of Canada
 The Halifax Insurance Company
 Hartford Fire Insurance Company
 (Monitor Ins. Group)
 London Canada Insurance Company
 The Great Eastern Insurance Company
 The London & Edinburgh General Insurance Company
 The Highlands Insurance Company
 The Home Insurance Company
 Seaboard Surety Company
 Insurance Company of North America
 Pacific Employers Insurance Company
 The Insurance Corporation of Ireland Limited
 Insurance Exchange Limited
 Insurance Corporation of Newfoundland Limited
 Community Life & General Insurance Co. Ltd.
 Beothic General Insurance Co. Ltd.
 Kanata Reinsurance Company
 La Capitale, Compagnie d'Assurance Generale
 La Compagnie d'Assurance Belair
 La St-Maurice, Co. D'Assurances
 Les Cooperants, Compagnie d'Assurances Generales
 Liberty Mutual Insurance Company
 Liberty Mutual Fire Insurance Company
 Lloyd's Non-Marine Underwriters
 (Kemper)
 Lumbermens Mutual Casualty Company
 Mercantile and General Reinsurance
 Company of Canada Ltd.
 Metro General Insurance Corporation Limited
 Midland Insurance Company
 Motors Insurance Corporation
 Munich Reinsurance Company of Canada
 National Reinsurance Company of Canada
 Norman Insurance Company Limited
 Norwich Winterthur Reinsurance Company
 Nova Scotia General Insurance Company
 Ontario Mutual General Insurance Company
 Orion Insurance Company Limited

Phoenix Assurance Company of Canada
 The Century Insurance Company of Canada
 Phoenix Assurance Company Limited
 Pilot Insurance Company
 Pool Insurance Company

(Laurentian)
 Provident Assurance Company
 The Laurentian General Insurance Company
 La Paix General Insurance Company of Canada

Prudential Assurance Company Limited
 (PRU-RE)
 Prudential Reinsurance Company of America

Reliance Insurance Company
 Royal Insurance Company of Canada
 British America Assurance Company
 The Globe Indemnity Company of Canada
 The Hudson Bay Insurance Company
 The Imperial Guarantee & Accident Insurance
 Company of Canada
 Law Union & Rock Insurance Company Limited
 The Liverpool & London & Globe Insurance Co. Ltd.
 The London & Lancashire Insurance Company Limited
 Cie d'Assurance du Québec
 The Western Assurance Company

SAFECO Insurance Company of America
 First National Insurance Company of America
 General Insurance Company of America
 St. Paul Fire & Marine Insurance Company
 Security Mutual Casualty Company
 Skandia Insurance Company
 Société Anonyme Française de Reassurances
 Société Nationale d'Assurances
 Sovereign General Insurance Company
 State Farm Insurance Companies
 State Farm Fire & Casualty Insurance Company
 State Farm Mutual Automobile Insurance Co.
 Strathcona General Insurance Company
 Sun Alliance Insurance Company
 The London Assurance
 Travelers Indemnity Company of Canada
 Travelers Indemnity Company
 Unifund Limited
 L'Union Canadienne, Compagnie d'Assurances
 United Canada Insurance Company
 The United Provinces Insurance Company
 United States Fidelity & Guaranty Company
 Fidelity Insurance Company of Canada

(Crum & Forster of Canada)
 United States Fire Insurance Company
 Herald Insurance Company
 Universal Reinsurance Group
 Abeille Paix Reassurances
 Netherlands Reinsurance Group (N.V.)
 The Nordisk Reinsurance Company Limited
 Storebrand International Reinsurance Co. Ltd.
 Union Reinsurance Company
 The Victory Insurance Company Limited

Utica Mutual Insurance Company
 Waterloo Mutual Insurance Company
 Wawanesa Mutual Insurance Company
 Western Union Insurance Company
 York Fire and Casualty Insurance Company
 Zurich Insurance Company
 Alpina Insurance Company

Mr. KOSTMAYER. Did you find in Ontario insurance company files or copies of medical records on American citizens living in the United States that may have been improperly obtained in this country?

Mr. STROSBURG. The paraplegic to whom I referred was from New York.

Mr. KOSTMAYER. He was an American citizen in a Canadian hospital?

Mr. KREVER. He suffered an accident on a Canadian road. Therefore, he was taken to a nearby Ontario hospital.

Mr. STROSBURG. I come from Windsor. When we had hearings in Windsor it was fair to say that some of the investigators in Windsor had gone to Michigan to obtain information.

Mr. KOSTMAYER. Did you find that copies of improperly contained Canadian medical records had been supplied to American affiliate companies in this country?

Mr. KREVER. I do not think so, Mr. Kostmayer.

Mr. KOSTMAYER. This is in some cases a problem of transport which affects both companies, some Canadian owned and some American owned. Is that right?

Mr. STROSBURG. I think so because one of the firms in question carries on a very extensive business in the United States.

Mr. KOSTMAYER. Do you think that the laws in your own country are adequate now? Is it too early to say?

I think you have provided us with a hefty book of Canadian statutes covering this general area. We are very much against laws in this country. I do not know whether you are going through that in Canada or not. We are very down on legislation here in the United States. We do not want to pass any more laws about anything here.

Mr. KREVER. We keep hearing about there being too many laws but that does not seem to stop the legislators.

It seems to me that my perception of whether a law is necessary does not count. I am not appointed to make that decision; legislators are elected for that purpose.

I think it is fair to say that the evidence makes it clear that many of the existing laws do not meet today's needs. Many of the existing laws are violated. It may be partly because the conditions that existed at the time of the enactment of those laws have changed. I think that is true in large measure.

It may be that techniques and technology which exist now did not exist in the days when that legislation was enacted.

One of the problems is that one cannot easily put one's finger on these provisions. Some of them are in statutes. Some of them are in regulations, subsidiary legislation made under the authority of the statute.

We constantly heard people saying, "We did not really know about the existence of such and such piece of legislation." I believe them. I think they did not. They said, "We are not trying to excuse our conduct because of our ignorance of the law."

Mr. KOSTMAYER. Can you give an example of where someone had been charged with a violation and said they were not aware there was a law making this illegal?

Mr. KREVER. We are not now speaking of charges. We are talking about notice given to people for the purpose of our hearings. We are not a charge-laying body; we are just an investigatory body for the purposes of acquiring information upon which recommendations can be made.

Mr. KOSTMAYER. You are trying to get some sense of whether these restrictions are generally regarded as reasonable or unreasonable or whether or not it would occur to an individual that this might be an illegal act that he was committing or whether they are so unreasonable it would not occur to the average person?

Mr. KREVER. Some citizens who testified said they were unaware of the provision in the regulation under the Public Hospitals Act. For example, statements were made by persons, including lawyers, that they were not aware that civil servants were obliged to take an oath of secrecy with respect to information that came to them in the carrying out of their duties.

Mr. PREYER. Will the gentleman yield briefly?

Mr. KOSTMAYER. Of course.

Mr. PREYER. Apart from legislation, there is something called the Hippocratic oath which hospitals and doctors operate under. Did you find that something has happened in the modern health care system so that the Hippocratic oath, which would prohibit the disclosure of medical information, is widely ignored today?

Mr. KREVER. I think the Hippocratic oath applies to physicians but not to hospitals in our jurisdiction. More important, the modern form of the Hippocratic oath is spelled out in a regulation under the Health Disciplines Act as it applies to physicians.

Turn to page 16 of this black booklet which I think you all have been provided. You will find two provisions which roughly cover the kind of concern that is reflected in the Hippocratic oath. Page 16 has a definition of professional misconduct. This section applies to the practice of medicine. The Health Disciplines Act covers five different health professions, but this part of the act deals with medicine. It says: "For the purpose of part 3 of the act"—which is the part that deals with the practice of medicine—"professional misconduct means:" Twenty-one says, "giving information concerning a patient's condition or any professional services performed for a patient to any person other than the patient without the consent of the patient unless required to do so by law."

That is an express statement of what is embodied in the principle of the Hippocratic oath, but under 31 you will see that there is a broader provision.

Mr. PREYER. Is this Canadian or Ontario law?

Mr. KREVER. Ontario. "Conduct or an act relevant to the practice of medicine having regard to all the circumstances would reasonably be regarded by members as disgraceful, dishonorable, or unprofessional."

Unless you construe this subsection 31 as applying to matters other than those dealt with in the preceding provisions, it may well cover the Hippocratic oath because the Hippocratic oath is in fact taken upon graduation from some medical schools, though not all. In any event, there is a code of ethics of the Canadian Medical Association and the Ontario Medical Association which incorporates the substance of the Hippocratic oath. It may be that viola-

tion of that is conduct which would be regarded as disgraceful, dishonorable, or unprofessional, if it is not fully covered by subsection 21.

The answer to the question is that physicians, under certain circumstances which anyone can understand, admitted violating either this provision or the Hippocratic oath. There may be circumstances in which some other interest larger than the interest of the patient may be thought to be a superseding interest.

As I am sure you know from your own experiences, this was largely the problem in psychiatry with mentally ill people.

Mr. PREYER. Excuse me, Mr. Kostmayer. I did not mean to interrupt your questioning.

Mr. KOSTMAYER. That is all right. Thank you, Mr. Chairman.

I do not want to prejudice your report. Maybe you will feel compelled not to answer this.

Do you find this information which you have collected shocking? Are you shocked by the abuses which you have seen in Canada?

Mr. KREVER. I am not sure that the way I feel now is the way I felt when I first learned about it. I may have become inured to it.

Mr. KOSTMAYER. Tell us how you felt when you first found out.

Mr. KREVER. I was very surprised, very much surprised.

Mr. KOSTMAYER. What is the current practice as far as patients having the right to access of medical information about themselves from an employer or a hospital in Canada? Are there laws covering this area?

Mr. KREVER. No; I am not sure it is professional paternalism or something more than that, but there is a strong belief on the part of health professionals that a patient ought not to have unrestricted access to his or her own records. I know that there is a minority view, but most of the persons with whom we have dealt and to whom we have put the question, no matter how liberal or conservative their views are in other respects, seem to share that view.

Mr. KOSTMAYER. They apparently do not feel the same compunction when giving the information to someone else, though.

Mr. KREVER. I am not sure that their mind is directed to it in the same way that it is when a patient asks to see it.

Mr. KOSTMAYER. I agree it is a puzzling situation when the patient about whom the file is being generated would be denied the information but the police would not be denied.

Thank you very much.

Mr. STROSBERG. One of the problems that seems to crop up is with the police. In Ontario the Public Hospital Act requires information be released only in certain specified circumstances. We had one hospital administrator who was really quite candid and came forward and said, "I had this situation. I had the police force in Ontario come to me and say there was a plane that was hijacked in the United States and that the person who was holding the plane and the passengers had been treated in this hospital in the psychiatric facility."

Under those circumstances there was no right to have access to that information, but he said he gave it to the people because they wanted to know what that person's psychiatric background was in order that they might better deal with him.

He said, "I was in breach of the law, and I knew I was in breach of my obligation. However, if it came up again tomorrow I would probably do the same thing."

We have seen some very difficult situations where there is breaking and entering or a smash-and-grab of a jewelry store or house. Someone has a bad cut. There is blood at the scene. You could tell that the thief was cut. The police go around to the local hospitals asking if anyone has had a jagged cut that night. Up until the establishment of this Commission, the hospitals cooperated. I am not so certain that cooperation is continuing now.

Mr. KREVER. There is no obligation in Ontario—and I think this is probably true throughout the Canadian provinces—to report gunshot or other suspicious wounds suggesting violence. That is an important difference.

Returning to the question whether or not the laws are sufficient, if you obey some of these laws to the letter—for example, the one under the Public Hospitals Act—it would be impossible for a parent to phone a hospital in the morning to find out how the parent's child spent the night unless there was written consent.

Mr. KOSTMAYER. I am sure you will be providing this information to us, but could you provide us with the names of any American-owned insurance companies with Canadian affiliates that were involved in your inquiry? I think you have that information there.

Mr. KREVER. That simply was a list of all the member companies of the Insurance Bureau of Canada.

Do we have it segregated so we can tell which companies—

Mr. STROSBURG. We would not discriminate that way.

Mr. KOSTMAYER. OK. Thank you very much.

Mr. PREYER. Following up on your last answer, I was interested in your comment on the relations of hospitals and patients. You told us earlier about insurance adjusters and private investigators. As far as relations with the police go, I gather what you were saying—and let me know if I am accurate—is that the situation generally prevailing with hospitals and police is this:

One, the hospitals know they are not supposed to release information to the police. However, two, they often do it to be helpful. They are not coerced by the police to do it.

Is that a fair summary of what you were saying?

Mr. STROSBURG. Yes. In most situations, in virtually all situations, it would be a question of voluntary cooperation. There are really two sides of the same coin.

First, there is a situation where the police come to the hospital and they say, "This is what we are looking for. Do you have that type of information?"

The other side of the coin is where hospitals contact the police and give information. Some people may say that you have to look at both of those situations differently, but virtually without question it was a situation where hospital employees were cooperating with the police.

Mr. KREVER. Mr. Chairman, it is fair to say that what evidence there is on this point suggests that the smaller the community the more likely the cooperation between the hospital and the police. You could probably go further. I am sure this is as applicable throughout the United States as it is in Canada. The smaller the

community, if there is a hospital in that community, the greater the likelihood is that there are so many members of the community who are employed in the hospital that our theoretical notion of confidential information in that hospital, when you think of a large, anonymous urban area, takes on a different complexion.

Mr. PREYER. Yes, I can appreciate that. In the Andy Griffith type community it is hard to keep a secret.

I understand that detective agencies are licensed in Ontario by the police. Have you found any example of detective agencies, under threat of license revocation, handing over medical information to police?

Mr. KREVER. The private investigators are licensed by a branch of the Ontario Provincial Police. I do not think that we found any evidence that the police ever went to them and said, "You'd better cooperate or your license will be in jeopardy." In fact, the evidence is that this branch does a reasonably good job now of protecting the information, but it is the subjective part of the question that I think is important.

We have had evidence from private investigators who say they cooperate despite the fact there is a section in their act prohibiting them from releasing information that they have obtained. They say they cooperate with the law enforcement agencies.

If a police officer were to ask an investigator who had in his files information on someone in whom the police were interested, the investigator would give that information. It may be that in the investigator's mind he feels he has to because his license depends on it. However, the reason given to us—and I have no reason to look behind it—is that, to use the words of one investigator in one prominent firm, "The last time I knew they were the good guys, so why shouldn't I give them the information?"

Mr. STROSBURG. It is certainly clear from some of the reports we have that information is flowing the other way, that is, from the police to the investigators. There were many examples of information that could only certainly emanate from the police through criminal records. That is not healthy information, but certainly there was that dialog.

Mr. PREYER. We have talked about access of private investigators and others to patients' records. What about the patient's access to his or her own records? Is that freely available in Canada?

Mr. KREVER. No; it is not.

Mr. PREYER. The patient has no right to see his or her own records?

Mr. KREVER. No. The practices vary. To me the most interesting series of questions and answers occurred with an administrator from one of the larger hospitals in Toronto in the witness chair. He was there for some other purpose, but I took advantage of his presence to find out what the practice was.

I think there is a relationship between confidentiality of health information and access to one's own records. The extreme nature of confidentiality is that the document or the record is so confidential that even the person whose information it is cannot have access to it. This was the exchange: The administrator was asked what the hospital's practice was when it received a letter from a lawyer asking for a copy of a former patient's record, the lawyer's letter

being accompanied by a freshly signed consent of his client and that hospital's former patient. The answer was that routinely, without any medical person being consulted, the medical records department of the hospital sends out the record.

Then this question was put to him: What would you do if, instead of having the lawyer write on his behalf, the patient himself came to the hospital or sent the letter in with a consent? Would you give that information? The answer was no. When asked why, he said, "We would want him to have some medical consultation, some professional consultation. We would ask him to come in and talk to the physician who would explain the record to him, but he would not get the record."

When asked how it was that they could give a lawyer for a patient a higher right than they gave the patient himself, he had no answer except he felt that the lawyer would use some professional judgment in what he released to his client. When told that if the client insisted on it, as I understood it, the lawyer would have to give that information, because of the relationship between lawyer and client, to the client, he said, "Well, sorry, but we expect professional judgment to be used."

Then I asked this: "Suppose you apprehend that the reason why the lawyer is writing in for the record enclosing the patient's consent is for the purpose of considering bringing a malpractice action against the hospital or a physician in the hospital. Would you release the record as routinely as you would if you thought he wanted it to sue a third party? He said no. I asked why not. He said, "Because it is not in the patient's interest to have that information." I asked, "How can you say it is not in the interest of the patient?" He said, "Well, because our courts would be——"

Mr. KOSTMAYER. It is not in the hospital's interest.

Mr. KREVER. That is the point. He said, "It is not in the patient's interest because our courts would be flooded with frivolous actions."

I asked, "Without the patient's consent in that situation, would you hand the file over to your insurer or your insurer's lawyer?" The answer was yes.

I asked, "Do you not see that there may be a conflict of interest for you to give it to your insurer or your insurer's lawyer without the consent of your patient and yet deny your patient the file on the basis it is not in his interest? Don't you think you are in a conflict-of-interest position and not in position to judge whether it is his interest?" The answer was no. He didn't see that.

Mr. KOSTMAYER. That is the legal mind.

Mr. KREVER. That is an extreme case. Others had varying policies but, generally speaking, they wanted consultation. The answer often was, "I would consult our lawyers."

Mr. PREYER. Respect for professional responsibility has come a long way from Mr. Shakespeare when he said, "First let's kill all the lawyers." That seems to be more the attitude in our country.

Is there a demand by patients for access to their records or are they supine on that point?

Mr. KREVER. It is very difficult to answer that question. I do not perceive a great demand. This is entirely impressionistic. On the basis of what we have received by way of submission, my guess is if

it were possible for patients to have easy access to records, then few of them would ask for it. That is very impressionistic.

Mr. KOSTMAYER. Is there any distinction made between psychiatric information and a record of shots given to the patient? Are we talking about all kinds of medical information here? We are not making any distinctions?

Mr. KREVER. In answering these questions I am talking about access to the very file, not to information in the file. If a patient wanted to know how many shots he had received from his physician, that would be given without any question. It is the very record I am talking about, not information from the record.

Mr. KOSTMAYER. I gather there are many instances in which there is no problem, in which the file is released to a patient after being reviewed by a doctor?

Mr. KREVER. The only cases in which that has become clear are cases in which the patient needs the information to bring proceedings against the third party who caused his injuries requiring him to be hospitalized.

Would you agree with that, Mr. Strosberg?

Mr. STROSBURG. Yes.

Mr. KOSTMAYER. Let me ask you one final question. In terms of providing information to the police, is this information provided generally for purposes of identifying suspects only or are there other justifications put forth by the police for receiving it or put forth by hospitals for providing it, other than the simple identification of a suspect?

Mr. KREVER. I think that is the primary reason, but I do not think we can say that is the only reason.

Mr. STROSBURG. It is not just a suspect in a particular crime. The question of security is a matter that police forces are often dealing with. That is when some visiting dignitary comes to town and they perceive that a person may be a threat. He has not committed a crime. They just want to determine whether or not he is likely to commit a crime.

Mr. KOSTMAYER. Would you give an example of what you mean? Is that possible?

Mr. KREVER. We have people in our society, as you do in yours, who write threatening letters and who do not like the establishment. They think persons in authority are the cause of their woes. They write letters saying that they are going to do something.

If I were a police officer charged with the responsibility of protecting a leader of a nation or a province or a visiting dignitary, I would want to know whether I should take that seriously or not.

Mr. STROSBURG. The other type of situation is this. With the Ontario Health Insurance Plan you probably have the greatest mass of health information in Ontario in one place. You also have updated names of employers because this is a benefit that goes with large employers. If it is a pay-direct plan, you have the home address.

When it comes to locating people, such as missing persons this is helpful. We had a situation of a person reported missing, and someone suggested we should check the Ontario Health Insurance Plan records to see if that person had a new address. It is the type of use of health information.

Mr. KOSTMAYER. Thank you very much, gentlemen.

Thank you, Mr. Chairman.

Mr. PREYER. The question of a patient's access to his records is complicated. There may be things in the record that the doctor would not want the patient to see because it would affect his health or emotional health if he knew about them. However, to allow his lawyer to have the records and then turn them over to him does not seem to be addressing the problem of patient access very directly.

Let me ask a question in one other area. Have you found any evidence of misuse of medical information by medical researchers? We have had some controversy about that in this country.

Mr. KREVER. Again, misuse is a difficult term to define because it may be that simply obtaining highly personal information without the consent of the individual is misuse.

I think probably it is fair to say that all of our research that is conducted in the health field is conducted by university-related researchers. Today almost every university where that kind of research is carried on has an ethics committee before which the application is brought. That very question is one of the concerns of that committee—and I speak as a person who has served on well over 1,000 of these committees.

However, from time to time it appears to me that information has been obtained without first consulting the patient. One of the most difficult problems I am now facing is that of devising some rules that will not stand in the way of necessary research. In the whole area of epidemiology I am persuaded that it is essential if we are to find the answers to a great many questions that we cannot now answer in the health field, that epidemiological research must go on.

I would hate to see rules enacted that would prevent that kind of research from proceeding. I am going to be having a great deal of difficulty in devising safeguards to permit the research to go forward but at the same time protect the rights of the subjects of that research.

Mr. PREYER. I think members of the staff may have some questions. I recognize Mr. Ingram.

Mr. INGRAM. Mr. Justice Krever, from how many witnesses have you received testimony?

Mr. STROSBERG. Over 560.

Mr. INGRAM. 560 witnesses, and the witnesses have come from various professions. Have you found generally that the testimony presented by those witnesses have been truthful and full to the extent of your inquiry or have you been required to go back after receiving the testimony to verify the facts presented to you?

Mr. KREVER. I do not have much hesitation in saying that almost all the evidence given under oath has been true. There were some exceptions. However, I think they were insignificant.

However, what we did find was this. Before calling these people as witnesses they are interviewed by investigators on our staff. Mr. Strosberg himself interviews people who could be witnesses.

When we have circulated questions to institutional witnesses and to witnesses, we have found that that first answers we received, almost without exception—and perhaps this says something about

human nature—were quick answers without doing the necessary research to insure accuracy. They were invariably not accurate in the sense that they were not the full picture. They may not have been intentionally misleading, but in their failing to give us the information that we really wanted or narrowly interpreting the questions, had we not gone further, we would have been acting on evidence which was not reliable.

However, once the witnesses were under oath, they underwent very searching cross-examination.

Mr. INGRAM. What you are suggesting guardedly is that the answers you received from your institutional witnesses require further check in order to paint the full picture.

Mr. KREVER. Yes. From my experience not only on this inquiry but on a longer Royal Commission in which I was involved from 1966 until 1970, it is fair to say that when you send out questionnaires to interest groups, individuals, and institutions that are within your terms of reference, then the answers you get, unless you put questions to them, are more in the nature of public relations answers. They are answers which will not reflect on the institution or person in an adverse way.

If you were to confine yourself to that kind of evidence, I do not think you would have a base of information on which you could really recommend sound policy.

Mr. STROSBURG. Mr. Ingram, you should not lose sight of the fact that, because the Commission was established under the Public Inquiries Act, there was a provision included that permitted the issuance of summons and also the application to a court for search warrants. We used this on numerous occasions.

Mr. KREVER. There is a sanction of contempt for not testifying or not taking the oath. We had to remind people about that sanction a few times.

I think the answer to your question is I am fairly satisfied that, by and large, the evidence given under oath was truthful.

Mr. INGRAM. Thank you.

Mr. PREYER. Mr. Gellman?

Mr. GELLMAN. I would like to ask a few questions just to clarify some points. The doctor that you mentioned, specifically, the one who went and examined the paraplegic, is it true that he was selling his information to insurance companies?

Mr. KREVER. Indeed he was.

Mr. GELLMAN. Is it fair to say your power to issue search warrants was crucial to your ability—

Mr. KREVER. Our power is to apply for the issuance of a search warrant to a county court judge. The kind of investigation in which we were involved was one with respect to which I think the existence of that power was crucial.

Mr. GELLMAN. I would like to ask a question with regard to the investigators who were doing pretext calling. Were any of these pretext calls by subsidiaries of American companies done at the direction of the parent company or with their knowledge or approval?

Mr. KREVER. That is a hard question to answer. The first part of the question I can answer with a "yes." Some of these practices

were carried on by investigators employed by a subsidiary, at least one subsidiary, of an American investigation company.

I have had some difficulty. I have invited the head officers or senior officers of the parent company to come to Ontario. However, I have no long arm statute which I can use to require that evidence. That invitation has not been responded to. In fact, I think it was rejected.

It is in law a separate legal entity in Canada, but the evidence was that only in 5 years from 1977, will it be operationally autonomous, so there is still some relationship.

Mr. KOSTMAYER. That is an American company?

Mr. KREVER. Yes.

Mr. KOSTMAYER. It is headquartered in this country?

Mr. KREVER. Yes.

Mr. KOSTMAYER. Can you tell us what company that is?

Mr. KREVER. It is a matter of public record.

Mr. KOSTMAYER. The name of it is what?

Mr. KREVER. Equifax.

Mr. KOSTMAYER. They refused to respond to your request to appear?

Mr. KREVER. The invitation was made to the Canadian officers to ask if the senior officer from the head office would come to Ontario. There were some negotiations in the form of letters. Finally the conditions under which they were prepared to do it were unacceptable, I thought, and the negotiations ceased.

Mr. KOSTMAYER. How do you spell that?

Mr. KREVER. E-q-u-i-f-a-x.

Mr. KOSTMAYER. I hope we will give them a chance to come and visit with us, Mr. Chairman.

Mr. PREYER. Mr. Morr?

Mr. MORR. Thank you, Mr. Chairman.

Mr. Justice, you mentioned a case of a doctor who obtained medical records directly from hospitals for an adjuster which were passed on to insurance companies. Do you have evidence that there was more than this one incident of a doctor obtaining this kind of information for an insurance company?

Mr. KREVER. I asked that question. I found it hard to believe that it would be limited to one physician. However, it seemed to me to be not unreasonable to limit the scope of our inquiry and not go into ancient history.

What probably can be said is this. Some of these practices began before the discovery mechanisms in our civil procedure were what they are today. The perceived need to know could not be satisfied by simply commencing a civil piece of litigation and resorting to the discovery mechanism. It seemed to me to be only fair that I ought not disturb people who are no longer practicing and who are retired by going back further than 10 years. Therefore, I limited my questions to that 10-year period.

I said, "Is there anyone or has there been anyone currently practicing who in the last 10 years did this kind of thing?" After inquiry the Insurance Bureau of Canada and I think the bar said the answer was that they could not come up with any other person.

Mr. STOSBERG. I do not know if it is clear, but that one physician did this on more than just one occasion.

Mr. MORR. I am aware of that. Thank you.

I have one question on the nature of your federal system.

Your inquiry relates to activities in the Province of Ontario. I notice that most of the statutes you provided the subcommittee are statutes of the Province. Does that mean there may be some variance among the Provinces in terms of the degree and kind of regulation of access to medical records?

Mr. KREVER. Yes. Theoretically there may be, but I think it is probably safe to say that the principles would be the same throughout the country.

Mr. MORR. Would you see the opportunity for some regional variance as a strength or a weakness?

Mr. KREVER. That is a nice question. I suppose in some ways uniformity of legislation throughout the country would be a good thing. However, there is the reality that needs are different in different parts of the country.

I suspect, however, that whatever results from our inquiry, the report that results from our inquiry will be read very carefully in the other Provinces and examination will be made to see whether or not some of the problems are the same. I think the answer will be that they are. It may have some influence in legislation that is enacted outside Ontario.

Mr. MORR. One of the issues that is addressed by a couple of the bills before the subcommittee is government access to medical records. I am curious. Do the military services of Canada or the officials in Canadian prisons have open access to medical records of soldiers or prison inmates?

Mr. KREVER. I have not inquired into the military because it is really outside of my terms of reference. We have a recent decision of the Supreme Court of Canada dealing with an inquiry in a sister Province, Quebec. It holds that provincial inquiry cannot inquire into a Federal agency in general terms about its methods of operation and so on.

As far as the prisons are concerned, there are Federal penitentiaries and Provincial prisons. We have not had any direct evidence but just from my general knowledge I would say that the prison authorities certainly have information about their patients. How easily persons who need not have it can have access to it is something which we really have very limited information about.

As far as the Ministry of Correctional Services is concerned, do you think the inquiry sheds much light on that?

Mr. STROSBURG. No. The only thing I can think of offhand is this. Each Provincial institution is responsible for the health care of the prisoner. the prisoner gets his health care under the Ontario hospital insurance plan number of the institution. Therefore, the institution has particulars of all of that information. Further than that we have not gone.

Mr. KREVER. After conviction if a person is sentenced to 2 years or more, he or she goes to a Federal institution. If it is anything under 2 years, it is to a Provincial institution.

Mr. MORR. I have another question. Because you have not made your final report, you may not be able to answer it. In grappling with this thing, it seems to me there are a variety of ways to protect the privacy of medical records. Based on the kinds of cases

of abuse you have seen, is this a problem that requires some new legislative remedy, improved enforcement of existing law, stronger adherence to ethical standards, or some combination of the three?

Mr. KREVER. All those things. There is not a single solution to the problem. Some of the existing legislation has outlived its usefulness. It does not cover current problems. I am talking about problems besetting a modern society. I think there will have to be changes in legislation.

I am not sure how you can strengthen the ethical requirements that now exist unless it is by education and making people more aware and perhaps providing stronger sanctions. All of the approaches you have mentioned will have to be resorted to. Even then, we will not be able to protect confidentiality completely. Human beings are involved. Whenever you have human beings involved, you are going to find conduct which ought not to occur from time to time.

Mr. MORR. Thank you for your answers.

Mr. PREYER. Mr. Ingram?

Mr. INGRAM. I have one last question. What is the going rate for a medical file? What does an investigator get paid these days for obtaining a medical file?

Mr. KREVER. It is quite clear that one of the effects we have had is that many of the practices we have uncovered have stopped. There has been something therapeutic in the mere inquiry, even if I never report. Some of the practices we have exposed will not recur. Some of them may recur when it is felt the heat is off.

Mr. INGRAM. What about prior to your inquiry?

Mr. KREVER. Prior? It varied.

Mr. INGRAM. I just want to test the incentives of the system.

Mr. STROSBERG. I do not think I would be exaggerating if I said it was a million-dollar-a-year industry in Ontario. We saw evidence in one case with one investigation company of hundreds and hundreds of thousands of dollars a year. The representations some agencies were making to their clients were that they were charging at an hourly rate, something like \$17.50 an hour or sometimes less.

When you examine the files, it is clear that you know a pretext call is made to one or two places and a substantial body of information is obtained. There may be a report that is three or four pages long. You cannot believe that there could be more than an hour spent. Yet the charge is \$250 or \$300 for the report. So although there is some representation made in the first instance that there is an hourly rate, in fact that is not how the system went.

I know some lawyers were surprised. They thought they probably were not charging enough for their services when they saw what the investigators were getting.

Mr. INGRAM. You are saying on the whole that the system was so loose and it was so easy to obtain medical records that the per-file cost was not very high?

Mr. STROSBERG. One of the saddest or funniest cases was a situation where one insurance company had a branch office on the east side of Toronto. It hired an investigation agency to inquire into a person who was making a claim against another person insured by this company. The investigation agency called the branch on the

other side of Toronto, the east side of Toronto. It was a branch of the same company.

So "A" insurance company was making an inquiry of the investigator. The investigator called A's branch on the other side of town, gets the medical information, puts it in a report, and sends it to the other branch and charges \$75 for it. Really the investigator was the middle man.

I think in part the insurers never knew that this was happening to the extent that it was happening. Because of the nature of the system, no one person saw all of the reports. Therefore, I think many people were as surprised as we were when we got them all together and started reading what was happening.

Mr. INGRAM. So the logging procedures in the hospital were bad, but they were just as bad in the insurance companies.

Mr. STROSBERG. There were no logging procedures.

Mr. INGRAM. Thank you.

Mr. PREYER. We thank you, Mr. Justice Krever and Mr. Strosberg, for this very helpful testimony. You have told us, for one thing, of examples of information obtained by pretext. That is straightforwardly wrong and evil.

Also, you have brought out that a lot of this is done, invasions of privacy, by people thinking they are being helpful, such as doctors, secretaries, and hospitals working with the police.

I am reminded of Dr. Samuel Johnson who once said something to the effect that mankind does not need so much to be taught as to be reminded from time to time. One of the values of your Commission, I think, is not only eliminating the pretext type wrong through legislation or other means, but it has also been very helpful in reminding us that there is such a thing as right of privacy. I get the impression we have gone to sleep on that in recent years. We have relaxed our guard a little bit.

That, along with the new technologically superb methods of communication and of copying records and so forth, has allowed us to drift in a situation where rights of privacy have not been protected. You are doing a good job in reminding us of that again.

Thank you very much for all of your information and for being here. I hope you will allow us to continue to maintain contact with you and communicate.

Mr. KREVER. Please do.

Mr. PREYER. We look forward to the Commission's final report. Thank you very much.

Our next witness is Mr. Marshall R. Crawford who is the senior director of Blue Cross and Blue Shield Associations.

Mr. Crawford, we are glad to welcome you here today.

STATEMENT OF MARSHALL R. CRAWFORD, SENIOR DIRECTOR, BLUE CROSS AND BLUE SHIELD ASSOCIATIONS

Mr. CRAWFORD. Thank you, sir.

Mr. PREYER. We will be glad to make your statement part of the record. You may proceed by summarizing it or reading it.

Mr. CRAWFORD. Mr. Chairman, in deference to the committee and for the sake of saving time, I will just submit the statement for the record and will be happy to proceed to any questions that you, Congressman Kostmayer, and the staff may have.

Mr. PREYER. We appreciate your statement.

To begin with, let me ask you a few questions about authorizations. There has been a lot of discussion about whether a patient can authorize a disclosure of his records. I assume when Blue Cross gets medical information ordinarily it has an authorization from a subscriber? Is it possible for you to get medical information without an authorization?

Mr. CRAWFORD. No, sir.

Mr. PREYER. Is that true of all insurance companies in this country?

Mr. CRAWFORD. I cannot answer for all insurers. I would assume that the legitimate insurance company would want to have an authorization. I am sure that anyone if they want to, by using various means, as you heard in testimony of the gentlemen here this morning, could probably get information in clandestine ways. However, I cannot think of an ethical company securing information that way. Certainly none of our plans do.

Mr. PREYER. The ethical practice of legitimate insurance companies is not to get any information without an authorization?

Mr. CRAWFORD. Yes, sir.

Mr. KOSTMAYER. Mr. Chairman, by authorization we are speaking of the personal patient authorization, not the authorization of the subscribing hospital. Is that correct?

Mr. PREYER. That is right. That is what I had in mind.

Mr. CRAWFORD. In most cases the hospital will have their own authorization to release to protect themselves.

Mr. PREYER. All of the medical bills that we have seen set certain requirements for authorizations. I would like to get your reaction to some of those.

Should the authorization be in writing, dated, and signed?

Mr. CRAWFORD. Yes, sir.

Mr. PREYER. Is there any problem if the authorization is required to specifically name the facility authorized to make the disclosure?

Mr. CRAWFORD. I do not see a problem in having to name the facility. I think it would be more flexible to be able to name the type of facility, such as hospital and so forth.

Mr. PREYER. A generic description.

Mr. CRAWFORD. That would allow more flexibility and not be as rigid.

Mr. PREYER. What about a requirement naming the person to whom the disclosure is to be made?

Mr. CRAWFORD. I have no problem with that. Here again, too, if you speak of insurance company or whatever would be the general purpose——

Mr. PREYER. do you think the authorization should describe the general purpose?

Mr. CRAWFORD. Yes, sir.

Mr. PREYER. Should the disclosure be for a fixed period, say, 6 months? I understand at the present time many authorizations are perpetual.

Mr. CRAWFORD. Depending on the type of disclosure you are talking about, Mr. Chairman. We probably would not have any problem with the time. However, I might point out that there is a difference in the way claims are paid and the way claims are filed.

sometimes the treatment period might extend for a long period of time.

I just had a personal experience 2 years ago where I had a shoulder operation, I had a lot of followup. It was almost a year and a half before the surgeon completed the followup and the therapy. He waited until it was all done before he filed the Blue Cross-Blue Shield claim.

Mr. PREYER. So you have no objection to having a fixed date, but it would have to be one flexible enough to allow time for full medical treatment?

Mr. CRAWFORD. Yes, sir.

Mr. PREYER. Would an answer to that be to cite a specific event occurring rather than a date—such as, payment of the claim or the end of insurance coverage?

Mr. CRAWFORD. When the purpose of the authorization no longer exists, then I would assume that the purpose for having the authorization should no longer exist.

Mr. PREYER. The question of Federal versus State action is one that gives us a lot of trouble in this field. The American Medical Records Association testified there was routine interstate transfer of medical records. I assume that Blue Cross has had that experience.

Mr. CRAWFORD. This is a rare occasion with us, I think, when you are speaking of medical records. We have a plan in each State. You will notice from our testimony that we have 69 Blue Cross and 70 Blue Shield plans.

Occasionally a patient or a subscriber who has coverage at his home plan will be on vacation or be in another State and will have to have service in a host plan. Claims information, sufficient, minimum information to pay that claim, will be transferred. Normally we just want to know if that person is covered, his contract number, and if he is entitled to the benefit.

Mr. PREYER. I would suppose Blue Cross probably has less interstate transfer of records than any other organization because you do have so many locations where the facilities are located.

Given the growing mobility of Americans and the growing regulation of the health care industry by the Federal Government, do you think Federal privacy legislation would offer any benefits of uniformity or efficiency that would be absent if we had different State laws?

Mr. CRAWFORD. Mr. Chairman, I will have to answer that question this way, if I might. We do not perceive a problem now.

Mr. PREYER. In different State laws?

Mr. CRAWFORD. No, sir. I assume that legislation would be designed to solve problems. If none exist that require Federal action, we would not want to go that route.

Traditionally insurance has been regulated at the State level. Any Federal action that would preempt that would be very much opposed by us.

Mr. PREYER. Do you think a model State law might be desirable? For example, this is the sort of thing I am thinking about. If each State has a different rule on authorizations, such as we were discussing earlier, then you might have to have 50 different forms of Blue Cross to fill out. I agree with your understanding that the

insurance industry has always been State regulated, and I think we want to keep it that way. However, do you think a model State law would answer some of the problems, such as the difference in forms you might have to fill out?

Mr. CRAWFORD. Yes, sir. I would answer that by stating our own experience. It is not that we endorsed it, but we were asked for and gave advice and counsel to the American Medical Association as they were developing their model law. We serve on an advisory committee to the National Association of Insurance Commissioners. They are in the process now of developing a State model law. We have been very active in that.

Mr. PREYER. There have been some instances where a hospital was asked to disclose records for legitimate use but was afraid to do so because of possible liability. Are you aware of this problem, if this is a problem? Would a law clarifying hospital use of records assist the hospitals in this respect?

Mr. CRAWFORD. Mr. Chairman, I would refer that to the facility and the institution. I am not that familiar with hospital law and hospital liability to adequately answer you and be informative and helpful.

Mr. PREYER. All right. Thank you. We will take that up with the hospitals.

The American Medical Records Association testified that sometimes insurance companies sought more information than was necessary. What is Blue Cross' practice in that respect? How specific are your requests for information?

Mr. CRAWFORD. Our requests for information are usually rather specific and limited only to that which we need to know to pay the claim. For instance, we would need to know the patient's name. We would need to verify that he is a member. We would want to have enough information to verify that the provider was a legally licensed provider, and know enough of the treatment or diagnosis to ascertain that it fits within the benefit pattern.

We do not encourage collection of information; we discourage it. So do all of our plans. I just recently reviewed a lot of the plans' policies. In their orientation and their continuous training program with their employees, they discourage the gathering of additional information. We would have a storage problem and we would not want it.

Mr. PREYER. I am glad to hear you do that in your training programs. Do you have any sort of written guidelines with respect to the kind of information?

Mr. CRAWFORD. Yes, sir. Almost every plan has its own policy. We have national policy. We are constantly developing ongoing procedures for claims collecting and for safeguarding all information. We are very security and privacy oriented.

Mr. PREYER. If those guidelines are not confidential, we would be interested in seeing a copy of them. They might be used as a model for others. However, if it is a confidential business secret, we will not press that.

Mr. CRAWFORD. I do not think there would be any problem at all. We would be very happy to submit them to the committee.

Mr. PREYER. We would appreciate that.

[The material follows:]

GUIDELINES ON PRESERVING
CONFIDENTIALITY OF MEDICAL RECORDS

Blue Shield Association

Approved: September 3, 1975

The issue of confidentiality of medical records has become a major concern particularly with the passage of the Professional Standards Review Organization law and impending legislation for National Health Insurance. Physicians, health insurance carriers, government officials and others are concerned about the potential threat of indiscriminate access to, and releasing of, sensitive patient data.

From its inception, Blue Shield has functioned as a responsible third party in assuring the confidentiality of the physician-patient relationship. Its use of medical data has been for two essential purposes: assuring the patient's right to proper payment of medical care and the review of the appropriateness and necessity of care rendered by physicians and other health care providers.

By virtue of this inclusion into the relationship, Blue Shield believes it should state publicly its policy and outline its current procedures for maintaining the confidentiality of medical data.

BLUE SHIELD POSITION

It is Blue Shield's position that the confidentiality of medical information it accumulates as a medical prepayment organization must be assured. The consequence of improper disclosure of medical data entrusted to a Plan can be detrimental to the patient, the physician and the particular Blue Shield Plan.

Each Blue Shield Plan, therefore, has a legal and ethical responsibility to administer effective safeguards. The aim of these safeguards is to permit authorized access to the information while maintaining the integrity of the confidential relationship between patient, physician and Blue Shield.

GUIDELINES OF CONFIDENTIALITY

Blue Shield Plans have always administered procedures to safeguard medical information. The intent of the following guidelines is to suggest a review of those procedures already in existence or to implement programs which may be necessary to achieve the objective of assuring the confidentiality of medical information.

PUBLIC ACCESS AND RELEASE OF DATA

It should be recognized that a Blue Shield Plan is a third party to the patient-physician relationship. Since Blue Shield's file is a secondary or duplicate copy of the physician's primary record, there should be no need to inquire into Blue Shield's file. Patient inquiries, therefore, regarding medical data should be referred to the physician. However, Blue Shield may nonetheless become involved in a formal request. Therefore, the following guidelines should be applied:

1. In general, medical information should not be released without a court order. When under a court order to release certain medical information, the Blue Shield Plan should release only the specific information requested. Release of data beyond that which is requested is a violation of the confidentiality of the data.
2. Medical information should never be released over the telephone.

Although the Plan may be authorized to release information, it must not do so by telephone. The Plan has no proof that the person receiving the data is, in fact, the individual authorized to receive it.

3. Medical information may be released in the aggregate form, however, requests for such data should be in writing and should include the purpose for which the data will be used.

It is frequently necessary to release medical data for purposes of research for the study of utilization trends. The data must not, however, identify patient, subscriber or physician.

Additionally, the Plan must know who is requesting the information, and to the best of its ability, assure that the data will be utilized in a proper manner. No valid determination to permit or refuse release can be made without this data.

4. Medical information may also be released to the extent necessary for appropriate peer review bodies to assist in claims determination relative to costs and quality of care.

In these situations, patient identification should be deleted. In addition, physician identification should also be deleted unless a peer review organization deems it essential to the review. When the identity of the physician is essential, the physician should be notified.

ADMINISTRATIVE RESPONSIBILITY

1. The Chief Executive Officer should appoint specific officers or administrative employees who have the responsibility of authorizing release of medical information.

This assists the Plan in making certain that release of information has been properly authorized and reduces confusion over the requirements that must be met.

2. When in doubt, the Plan should rely upon its legal counsel to determine the appropriateness of a request for information and the extent of any release of medical data.

This assures the Plan that questionable requests receive the necessary legal considerations and that any release of information has met the proper legal requirements.

INTERNAL ACCESS AND HANDLING OF MEDICAL INFORMATION

1. Access to medical information should be limited to a "need to know" basis.

Confidential information implies restriction to the least number of people necessary. Indiscriminate access merely compromises those procedures intended to safeguard the data.

2. Adequate orientation and training programs should be developed and maintained which emphasize the sensitivity of medical records and the need to maintain their integrity.

The orientation and training program on the need to preserve confidentiality should be given high priority and consist of both oral and written presentations. In addition, periodic re-orientations on confidentiality of medical data should be conducted. If safeguards are not adequately met, an invasion of privacy may occur involving both the employee and the Plan.

3. Plan employees should seek only those data necessary to adjudicate a claim, case or utilization patterns and profiles.

For example, if the Plan needs only a discharge summary or consultation report, it should not ask the hospital or physician for the entire record. To do so, not only creates storage problems, but also places unnecessary burdens on those mechanisms which are meant to insure confidentiality.

4. Adequate security precautions should be implemented to limit access to computers and data banks to those operating the systems.

The massive amount of information collected by a Plan requires the use of automated data systems to perform its functions in an efficient and timely manner. This consolidation of data in computer storage banks or magnetic tapes facilitates easy access to, and retrieval of, information by anyone capable of operating the systems or copying tapes.

5. Employees should be encouraged to handle confidential data in a professional manner.

Confidential information should not be discussed except for the purpose of adjudicating a claim.

In addition to a review of existing safeguard procedures, Plans are encouraged to communicate their activities to their subscribers and physicians. It is essential that their understanding and cooperation be gained in order that any procedures implemented by the Plan may be effectively administered.

Mr. PREYER. You mentioned in your statement, which is in the record, that legislation should be careful not to restrict unduly audit or review activities. That is certainly an understandable position.

What sort of audit and review functions do you carry out? Let me put it this way. To carry out those functions do you have to have identifiable medical information? Do you have to have somebody's name?

Mr. CRAWFORD. If it is an internal audit, naturally we have that. It is treated confidentially. For outside audit we would delete the identifier. We are concerned with cost, as everyone is these days. That is our major audit purpose. We also have to have certain information for paying the claim.

Mr. PREYER. We do not want to discourage your concern with holding down costs.

Mr. CRAWFORD. In outside audits the personal identifiers would be deleted in most cases.

Mr. PREYER. In the course of paying claims is the information which you receive ever used for any other purpose?

Mr. CRAWFORD. No, sir.

Mr. PREYER. You do not make it available to researchers, for example?

Mr. CRAWFORD. Not the claims information per se. We sometimes will give information in the aggregate. This is done sometimes for groups to determine their experience and the utilization rate, but personal identifiers would be gone.

Mr. PREYER. That would not be identified?

Mr. CRAWFORD. We would not release that without the subscriber's permission.

Mr. PREYER. Have you noticed in recent years a change or a growing awareness among hospitals, doctors, nurses, and patients concerning privacy?

Mr. CRAWFORD. Yes, sir. We have been responding to that within the plans and at the national organization, too.

Mr. PREYER. So there has been more demand for privacy protection, and you were seeking to respond to it in some of the ways you indicated?

Mr. CRAWFORD. Yes.

Mr. PREYER. Do you feel we need a law providing for confidentiality of medical records? Do you feel that would give patients more confidence in doctors and hospitals?

Mr. CRAWFORD. No, sir, I do not. I think that the confidence that the patient would have in the hospital and the doctor has to come from trust. If the patient knew that the doctor was treating him and keeping it confidential simply because the law said so and not because the doctor was ethically bound, morally bound, and personally felt obligated to do it, then I personally would not like to have that situation. When I go to my doctor, I would like to think that he feels that way inside.

Mr. PREYER. I would certainly agree with you that trust is what is necessary to have complete communication between the patient and the doctor. That is what we have to have if we are going to have a proper result.

One concern is that if the patient knows what may happen to information which he gives his doctor, if he knows it is going to be safeguarded, then that will free up his communication with the doctor.

Let me ask a question in one other area and then counsel may have questions. This is the questions of cost of a possible medical records privacy bill. What effect do you think the bill would have on insurance companies from the point of view of cost? I am talking about a medical records bill requiring authorization for disclosure and so forth.

Mr. CRAWFORD. Mr. Chairman, I cannot answer that with any specifics at this time because we have not done an analysis of it. Under the current situation we do not know.

However, in a plan that is a carrier or intermediary for a Government program, such as medicare, you get an inquiry now and you have to know the Freedom of Information Act, you have to know the Privacy Act, and you have to know the disclosure regulations from SSA, as well as State law. I would assume that if you added another layer to this inquiry internally, then there might be a slight cost; but I cannot tell you what it would be. It very easily might to handled administratively.

Mr. PREYER. All of these other laws are already in effect. The mechanism is in effect set up now to deal with these sort of questions.

Mr. CRAWFORD. The adjustment might be slight.

Mr. PREYER. Mr. Ingram, do you have questions?

Mr. INGRAM. Due to the hour, Mr. Chairman, I have no questions.

Mr. GELLMAN. I would like to ask one question. Most of the bills that are being considered require the medical care facility to maintain a copy of an authorization to disclose information about a patient. Is that normal practice now?

Mr. CRAWFORD. Yes, sir, I think it is. This does not give us a problem. The only thing I would ask the committee and staff to consider it not to require the facility to keep more records than are necessary, not duplicate what they already have. That does add to cost.

Mr. GELLMAN. That is one of our concerns. Thank you.

Mr. PREYER. Mr. Morr?

Mr. MORR. Mr. Chairman, I just have a couple of questions. One, I understand that commercial insurance companies exchange some information through an operation known as the Medical Information Bureau. Does Blue Cross participate in MIB?

Mr. CRAWFORD. No, sir.

Mr. MORR. We heard from Dr. Jerome Beigler of the American Psychiatric Association. In his testimony he suggested that one of the things we ought to consider is having a psychiatric notes exception from the access provisions that we are considering in these various bills. Is there anything in a doctor's psychiatric notes that would be valuable to you as an insurer that provides payment for psychiatric care? Would it be a problem if we included a psychiatric notes exception?

Mr. CRAWFORD. No, sir, it would not. We very seldom—it would be a rare occasion—see or get the notes.

Mr. MORR. Under contract with the Government you are involved with medicare, medicaid, and certain other Government programs. You have talked about how you as a company try to prevent collecting unnecessary information. Do you have any feel for the amount of information the Government collects through you in your contract role? Do you feel Blue Cross would collect as much information? Is the Government collecting too much information?

Mr. CRAWFORD. I cannot answer that specifically. In our role as contractors we only collect and only give to the Government that which we are required to do under the contract. That normally would be the type of information we would gather to process the claim if it was private business.

Mr. MORR. Thank you very much.

Mr. PREYER. Thank you very much, Mr. Crawford. We hope you will allow us to keep in touch with you.

Mr. CRAWFORD. Yes, sir, I will be happy to do so. Thank you very much.

[Mr. Crawford's prepared statement follows:]

PREPARED STATEMENT OF MARSHALL R. CRAWFORD, SENIOR DIRECTOR, BLUE CROSS
AND BLUE SHIELD ASSOCIATION

Mr. Chairman and members of the Committee.

I am Marshall R. Crawford, Senior Director, Legislative Services, the Blue Cross Association and the Blue Shield Association. We appreciate the opportunity to comment on the Federal Privacy of Medical Records Act, and more specifically, on the broader issue of confidentiality of medical records.

The Blue Cross and Blue Shield Associations are the national coordinating agencies for the 69 Blue Cross and 70 Blue Shield Plans in this country. These Plans provide privately underwritten health care coverage to about 85 million Americans, and serve almost another 20 million as fiscal agents or intermediaries for the Medicare, Medicaid and CHAMPUS programs. Thus, the Plans serve about half the U.S. population.

We share the general concern you have about the issue of privacy and confidentiality of medical records. All not-for-profit Blue Cross and Blue Shield Plans have a long history of commitment to the privacy of our subscribers.

Like everyone else, we who utilize personal-related information, are faced with the growing concern over confidentiality on the part of the public. However, we are not new to the subject.

For decades, we have maintained successfully our subscriber's rights to privacy. We are proud of our record and proud of our efforts, such as constant maintenance, review of existing procedures, and implementation of new safeguards, all aimed at maintaining and enhancing that record for the future.

Mr. Chairman, we believe that it would be helpful to explain the type of data we collect and how they are used.

Most third party payors, especially Blue Cross and Blue Shield Plans, have limited information on an individual in the first instance. We collect and maintain only information which is reasonably needed to fulfill our responsibilities. In addition, as a general rule, we disclose information only to such sources as are absolutely necessary, on a need-to-know basis, to fulfill their responsibilities in the patient-provider-payor relationship.

Insurance firms and non-profit service organizations, like Blue Cross and Blue Shield Plans, accumulate and use subscriber information at two principle points of operation: enrollment and payment of claims.

Insurance underwriting involves two separate decisions: whether the insurer wants to insure the applicant and at what price. For Blue Cross and Blue Shield Plans, information requirements for enrollment purposes is, for the most part, a far less sensitive issue.

The majority of our subscribers are in groups - where simple card forms providing name, address, name of dependents and social security number are requested, along with needed payroll deduction authorizations. Conversion contracts, for those who leave employment, generally include the same information. When an individual moves from one Plan area to another, a special transfer agreement between Plans permits the subscriber to become enrolled in the new area without the need to supply extensive personal information. When an individual applies initially to a Blue Cross or Blue Shield Plan, medical history information for underwriting purposes may be requested.

When a claim is paid, additional information is needed. The information must be sufficient to establish the fact that services billed were included under the benefit agreements, necessary and warranted, and actually delivered. Information needed includes identity of the patient, the physician, and the facility, diagnosis, treatment description, length of stay, and billed charges.

Specifically, a Blue Cross and Blue Shield Plan would need the following information to pay a claim:

- Membership Eligibility - Each claim must contain sufficient information to enable the Plan to identify the patient as a member at the time the service was rendered, e.g., name, contract number, relationship to contract holder, and date of service;
- Provider Eligibility - The claim must supply enough information to verify the name, address and credentials of the provider;
- Description of Service Rendered - Members are entitled to different benefits depending upon the nature of the contract under which they join the Plan. Inappropriate expansions of that benefit range would come at the expense of other members of the Plan. Therefore, each claim must describe the service rendered, the diagnosis upon which it is based, and its medical necessity;
- Amount Charged for the Service - The claim must also reflect details on the service provided to verify the appropriateness of claim charges;

- Benefit Contract Modifiers (deductibles, co-payments, etc.) - Some payment programs requested by the public (such as Major Medical coverage), require that the Plans accumulate specific additional claims processing information. For example, some programs call for a comparison of cumulative deductibles and co-payments against a fixed (or variable) limit on member out-of-pocket expense; others require the accumulation of such costs to administer "corridors" between basic and catastrophic benefits, and others require coordination with other coverage the individual may have;
- Government Reporting Requirements - In their role as contractual intermediaries and carriers for government programs, the Plans are required to collect those items of personal information specified by the relevant contract, statutes, or regulations.

In addition to the purposes outlined above, Plans need to accumulate aggregate data for research and development purposes. Benefit modifications and new coverages depend on informed judgment based on such data.

Mr. Chairman, although this has been a brief explanation of rather complex procedures, it typifies the information our Member Plans collect and use.

Another element to the confidentiality issue is the identity of the sources of subscriber information received by Plans. For example, who gives us the enrollment and claims information?

Subscriber information needed by a Plan is collected directly from the member or in the case of group coverage through his employer or other group. In addition, non-group members are typically requested to give written consent for the Plan to obtain and verify their medical histories as required for risk assessment.

Medical/claim information comes to the Plans both from individuals and from providers, depending upon the benefit and the provider involved. Some benefits, such as major medical programs, typically require submission of the claim by the member. Similarly, members submit claims for benefits rendered by providers who are not participants in Plan programs. However, the majority of medical information comes to a Plan by means of claims submitted by providers.

A small percentage of information received by a Plan for group coverage comes from insurance companies for the administration of coordination of benefits provisions in group coverage. These provisions are cost control devices to prevent double payments which could occur, for example, when a husband and wife both work and have separate family health coverage through their employers.

Plans may sometimes disclose certain information in performing their duty as third party payors. This is done in the following circumstances.

To better serve their subscribers, Plans have agreed to a reciprocal arrangement to provide the best possible service to members who require health care treatment outside the geographical area of the Plan through which they were enrolled (the "Home" Plan). In such a case, the Plan delivering services

acts as the "Host" to the member and later bills the "Home" Plan for the services rendered. This practice requires the exchange of minimal coverage and claim information between the Home and Host Plans.

Many Plans also serve as intermediaries and carriers in a number of government programs, such as Medicare. In these roles, they are required by contract, regulation and statute to make reports to the controlling government agency on the utilization of program benefits. Typically, these reports require and include personal information.

In addition, Plans generally are under the regulatory control of their respective state insurance commissioners who have the responsibility to protect the public by verifying that insurers are operating fairly and are financially solvent. Most commissioners have legal access to Plan records for periodic audit purposes and complaint handling.

Finally, Plans may be required to surrender subscriber information by a valid court order or subpoena or by the terms of an enforceable order of a government agency, such as a summons issued by the Internal Revenue Service. These releases are generally made only upon approval of Plan legal counsel, and it is growing Plan practice to notify the affected member in the event of such a release.

Mr. Chairman, we have identified the information Plans collect and use, and have indicated the circumstances under which it may be disclosed. At this point, we would like to state very emphatically that Plans recognize and acknowledge the sensitivity of the personal and medical information with which they are entrusted. As a result they maintain and expect to continue

to maintain high levels of control over that information. Confidentiality measures derive from both formal and informal standards, and while they may vary somewhat from Plan to Plan, common principles and safeguards are followed. Many Plans have been sensitive to and in compliance with the Privacy Act of 1974, because they serve a large number of people through such government programs as Medicare and Medicaid. Collectively, approximately 13 million under Medicare and 5 million under Medicaid are served. We also serve 1.8 million Federal Government employees, representing approximately 5 million people, as carriers for the Federal Employee Health Benefits Program.

Plans employ a confidentiality control known as the "need to know principle." Briefly, it is applied in two forms. The first is that a Plan should obtain and retain only such information as it needs to carry out its role. The second is that, within a Plan, employees should be allowed access only to such information as they need to carry out their assigned tasks.

Plans also have specific guidelines although they are likely to differ somewhat. The following is an example of the specific employee guidelines used. It is a verbatim extract from one Plan's employee orientation program.

"To perform the job of providing health care coverage to our subscribers, the employees (of the Plan) are entrusted with confidential medical and financial information. The same ethics that apply to doctors and hospital personnel apply to our employees.

A person's state of health is his personal business. The diagnosis and treatment of his illness is a matter between him, his doctor, and other health care personnel who are helping him to get well. Releasing the medical information included in a person's claim form, whether to the individual himself or to anyone else, is a serious breach of confidence with providers and could cause the individual unnecessary embarrassment or worry.

Company policy regarding medical and financial data will prohibit (except in clarification of data to a provider) the disclosure of any information about:

- (a) The diagnosis of the patient.
- (b) The treatment of the patient.
- (c) Physician's charges.
- (d) Hospital records.
- (e) Physician patterns of practicing.
- (f) Total annual earnings of physicians.
- (g) The status of the subscriber's employment (where he works, what he does or whether he is laid off and his salary).
- (h) The pay scale of our employees.
- (i) Member's level of coverage (except to providers and the member himself)."

This Plan's training program includes videotaped instructions reiterating these points and reminding Plan employees that violations of these principles can lead to their dismissal.

We have a strong commitment to confidentiality at the national level. For example, both National Associations testified before the Privacy Protection Study Commission where we made public our concerns and dedication to the principles of privacy and confidentiality. Plans have also been issued extensive guidelines for physical and data security to prevent unauthorized access to sensitive personal information.

In addition, a formalized position has been issued by the Blue Shield Association through "Guidelines on Preserving Confidentiality of Medical Records." The Guidelines, in part, state that each Plan "has a legal and ethical responsibility to administer effective (confidentiality) safeguards. The aim of these safeguards is to permit authorized access to the information while maintaining the integrity of the confidentiality relationship between patient, physician, and Plan." They spell out specific policy for each of the following principles:

- (a) In general, medical information should not be released without a court order.
- (b) Medical information should never be released over the telephone.
- (c) Medical information may be released in the aggregate form based upon written and legitimate requests. Such data must not identify patient, subscriber or physician.
- (d) Medical information may also be released to the extent necessary for appropriate peer review.
- (e) Access to medical information should be limited to a "need to know" basis.
- (f) Adequate employee orientation and training programs should be developed and maintained.
- (g) Plan employees should seek from providers only those data necessary to adjudicate the claim, case or utilization patterns and profiles.
- (h) Adequate security precautions should be implemented to protect access to computers and data banks.
- (i) Employees should not discuss or handle confidential data except for direct job purposes.

Blue Cross and Blue Shield have a long-standing commitment to the principles of confidentiality of information of our subscribers. We are applying these principles at all levels of our enterprise. We will vigorously continue this policy.

With respect to the Federal Privacy of Medical Records Act, the Blue Cross and Blue Shield Plans and their two National Associations are on record in testimony before the Federal Privacy Protection Study Commission as being in opposition to extension of the Privacy Act of 1974 to the private sector. The imposition of mandatory administrative procedures under the law (and other proposals) would create additional burdens on Plan operations without providing appropriate benefits to the public. The Plans' ability to serve their communities would be impaired by the imposition of mandatory procedures such as:

- (a) Registration of systems and/or files using personal information.
- (b) Restrictions on modifications or enhancements to such systems and/or files.
- (c) Limitations on the use of personal identifiers (e.g., social security number).
- (d) The logging of "non-routine" accesses to personal information.
- (e) The establishment of a regulatory body to review and control the privacy practices of the private sector.

Moreover, such administrative measures would not add in any way to the protection of the personal privacy of the individuals so affected. In fact, these measures contribute to the threat to privacy by drawing public attention away from the real issues, i.e., the confidentiality abuses themselves.

An effective ethical standard would accomplish greater protection by the identification of potential abuses and the mobilization of public and professional pressure to eliminate their commission.

We would now like to offer a few additional comments and a few specific recommendations regarding H.R. 2979 for your consideration.

First of all, we see as one of the major concerns a need to avoid any further duplication of regulations. As we have already commented to HEW in response to their Operation Common Sense, only one set of regulations is needed to cover appropriate privacy and disclosure. Combining the present regulations into one would protect the public's right to privacy and appropriate information, and eliminate misunderstanding and duplication. This bill could have the effect of adding another layer to an already complex and difficult situation.

Furthermore, in order to satisfy the requirements of some sections of this bill, it appears that there may be an added cost factor for some facilities to absorb. This is contradictory to efforts to contain health care costs, particularly at the hospital level.

Finally, since this bill would amend the Privacy Act, we assume that it would apply only to government program patients. Some feel, however, that this bill might be construed to apply to all patients, government or private. This point should be clarified. In our following comments, we will assume that H.R. 2979 applies to government program patients only.

Here are our comments on certain sections of the bill before this Committee.

Part A Sec. 101(9)(B) - Currently Blue Cross Plans, Blue Shield Plans, and commercial insurers are treated as sources of information. As we explained earlier, we gather only information necessary to pay claims. This classification has created unnecessary duplication of procedures. Therefore, we ask that intermediaries and carriers be specifically excluded from the definition of "medical care facility."

Sec. 101(10)(A)(i)(ii) - We feel that the definition of "medical record" should be clarified so that items such as charge slips, billings, etc. would not be construed to be subject to these provisions.

Sec. 102(a) - We suggest substituting "access and disclosure" for "confidentiality" on lines 13 and 14 for clarification and consistency with other sections. One other comment on this section. Many states and non-federal entities have provisions for access and disclosure already in operation. We recommend that such provisions not be made redundant by this provision.

Sec. 103(1) - The definition of "minors" may need special attention, particularly in view of the strides being made by society with regard to children's rights. We urge further consideration be given.

Part B Sec. 111(b) - This section would allow the medical care facility to deny individuals the right to inspect their medical records under certain circumstances. We feel that the intermediaries or carriers should not be involved. Individuals should be referred to the primary source, the providers. However, if the definition of "medical care facility" is clarified to exclude carriers and intermediaries as we have recommended, this will not be a problem.

Sec. 111(c) - With regard to this subsection and subsection (b) we would like to raise the question of who would make the determination of denial to inspect an individual's medical record.

Will it be the attending physician, or a specialist who is only treating the patient for a special condition, or a consultant? Further clarification of congressional intent is needed.

Sec. 115(a)(3) - We suggest adding the words "where appropriate" after "disclosed" on line 5. Many times an individual may authorize disclosure to an insurer and not know the name of the person who will be receiving it. Hence, the phrase would provide some flexibility for this situation.

Part C Sec. 123 - It could be argued that revealing the location of an individual in a facility could indicate the nature of treatment provided, especially in cases of psychiatric treatment, since these rooms are usually in a special section of the hospital. This also applies to the provision of services. Therefore, we recommend eliminating those qualifiers from this section.

Sec. 124(b) - If a person obtaining medical records in accordance to subsection (a) needs personal identification information on it, we feel this should be justified in advance. If personal identification information is not needed, then this should be removed from the record by the facility before it is released. (This comment applies also to Sec. 125(b)(2).)

Sec. 132 - A provision should be added to permit carriers and intermediaries to receive appropriate information for the purpose of processing claims relating to medical services received by individuals under government programs.

Mr. Chairman, that concludes our comments on H.R. 2979.

We do not feel that additional legislation is necessary to protect the privacy of the information gathered on individuals. The private sector, in general, and Blue Cross and Blue Shield Plans in particular, are doing everything possible to assure this.

If, however, it is felt that it is necessary to pass some legislation we have a list of elements to propose which we feel are essential in any legislation on privacy, some of which are already included in H.R. 2979. We also urge that consideration be given to the concerns already expressed in our statement here today.

- We feel that physical safeguards are important.
- Legislation should allow discretion in the release of sensitive information to the patient which may be potentially damaging to him.
- Information should not be unduly restrictive for research purposes.
- Legislation should not prohibit legitimate audit and review functions.
- Legislation should be flexible and not place undue burdens on providers, patients, and insurers by requiring too many forms, copies, authorizations, and other similar demands.
- Legislation should deal with principles and standards, encourage voluntary efforts, and allow states to carry out any needed day-to-day administration.

Mr. Chairman, thank you for the opportunity to comment on the bill and to offer our suggestions and recommendations on the confidentiality of medical records.

Mr. PREYER. Our final witness today is Mr. Jonn Shattuck, the director of the American Civil Liberties Union.

Because of the time situation, I regret that we will not be able to go into questions with Mr. Shattuck which we would like very much to do. I hope that he will allow us to put his statement in the record so that he we can begin to go to work on that. Then we will invite him back on another occasion.

STATEMENT OF JOHN H. F. SHATTUCK, DIRECTOR OF THE WASHINGTON OFFICE OF THE AMERICAN CIVIL LIBERTIES UNION

Mr. SHATTUCK. I would be pleased to do that, Mr. Chairman.
[Mr. Shattuck's prepared statement follows:]

PREPARED STATEMENT OF JOHN H. F. SHATTUCK, DIRECTOR OF THE WASHINGTON
OFFICE OF THE AMERICAN CIVIL LIBERTIES UNION

I am grateful for the opportunity to testify this morning on an issue of great importance to the American Civil Liberties Union. I am the Legislative and Washington Office Director of the ACLU, a nationwide, non-partisan organization of more than 200,000 members devoted to the protection of individual rights and liberties. I am also the author of a textbook, Rights of Privacy.

For many years the ACLU has played an active role in the effort to safeguard individual privacy against intrusion by government and private recordkeeping practices. Through our Project on Privacy and Data Collection, to which I served as Counsel from 1973 to 1976, we have provided legal representation to many individuals whose rights and interests have been adversely affected through the collection and misuse of personal data by employers, credit reporting agencies, insurance providers, government agencies and others. We have also sought to publicize the erosion of privacy in a society where personal information is increasingly recorded by third parties and used for a wide variety of purposes without the knowledge or consent of the person involved.

We congratulate the Subcommittee and its Chairman for providing strong congressional leadership on privacy issues and commend you for conducting these hearings on perhaps the most sensitive of all privacy issues, the confidentiality of medical records. In my testimony this morning I will attempt to define the scope of the medical privacy problems, to

explain why and what aspects of it are in critical need of legislative action, and offer some preliminary comments on the separate legislation which has been proposed in this area by the Carter Administration and by Chairman Preyer (H.R. 2979).

Scope of the Medical Privacy Issue

Of all personal records, medical records are easily the most sensitive and thus the most vulnerable to abuse.

According to the Privacy Protection Study Commission, an estimated 1,056,000,000 patient visits are made every year to physicians in their offices and in private and governmental hospitals and clinics. Over a million people live under medical supervision in nursing homes. Schools, employers, the armed forces, prisons, and other custodial institutions provide medical and psychiatric services for their populations. The number of records generated by these doctor-patient contacts is, in the Commission's phrase, "staggering".

For most patients, the first privacy problem that they encounter is their inability to obtain access to their own records. But this problem, to which I will return, is less serious than the threatening intrusions into personal matters that arise from the increasing number of uses to which medical records are put. These uses have nothing whatever to do with the doctor-patient relationship which generated the records in the first place.

A partial list of the most common "third-party" uses of medical records includes:

Insurance companies. Both to establish an applicant's eligibility for health, life, and disability policies, and to process claims under such policies, insurance companies require extensive medical information from the patient's physicians and psychiatrists and from his hospital records. So much medical information is collected by insurance companies, in fact, that the industry maintains its own giant medical databank, called the Medical Information Bureau.

Government service payers. The government agencies which finance and administer Medicare, Medicaid, Social Security disability, and workmen's compensation programs all require the submission of patient treatment records as a prerequisite for authorizing payments. State and federal agencies which administer special publicly-funded medical services, such as treatment for drug addiction and alcoholism, mental health problems, and physical handicaps, frequently require access to or information from the patient's records.

Welfare agencies. The many government agencies involved in the administration of welfare and social services programs often require detailed information about their clients' medical problems and treatment.

Professional accrediting agencies and review boards. Both public and private agencies use patient records to evaluate the quality of professional services provided by doctors and health care facilities.

Researchers. Many medical research projects use patient records. Usually, the information can be provided to researchers in aggregate statistical form, but some projects utilize individual, identifiable records.

Employers. Applicants for employment are often asked to fill out extensive medical questionnaires and in addition to give prospective employers access to their physician and hospital records. Both applicants and current employees may be required to undergo examinations by company doctors. Employers also obtain diagnostic and treatment information about their employees through claims submitted under company-provided insurance plans.

Credit reporting agencies. Private credit reporting agencies compile medical histories and claims investigations for employers and insurance companies, frequently containing information taken directly from physician and hospital records.

Public health and law enforcement agencies. Numerous state laws require hospitals, physicians, and other health care providers to report certain kinds of diseases, injuries, and treatments to a public health department or even directly to the police. These include venereal disease, drug abuse, suspected incidents of child abuse, gunshot wounds, a long list of contagious and epidemic diseases such as typhoid and scarlet fever, abortions, and prescriptions for certain kinds of drugs. Government agencies, such as the National Institute for Occupational Safety and Health, have access to employees' health records to use in studies of environmental and occupational hazards. Police departments frequently demand--and receive--access to medical records in the course of criminal investigations.

Licensing agencies. State occupational licensing requirements usually include the submission of medical and psychiatric records.

Institutions. When medical services are provided in an institutional setting, such as a school or college, prison, or the armed services, non-medical personnel within the institution often have access to a patient's records.

Databanks. As a routine adjunct to many of the third-party uses of medical records just described, computerized registries or databanks of particular kinds of patients are maintained by a variety of public and private agencies, ranging from state and local governments to insurance companies and national charities. There are, for example, registries of patients receiving certain prescription drugs, abortion patients, cancer patients, handicapped persons, psychiatric patients, drug addicts, and clients of state-financed medical services. Such patients are seldom even aware that these databanks exist.

This rapidly expanding use of medical records outside the doctor-patient relationship has resulted in a pattern of real and potential abuses and injuries to patients. These are illustrated by some of the cases handled by or reported to the ACLU in recent years:

- A man reported to the New Jersey Civil Liberties Union in 1974 that he had lost his job with the Newark Board of Education and had been denied two life insurance policies because a credit reporting company had obtained access to his medical records without his knowledge or consent, and had reported to his employer and prospective insurers that he suffered from an "emotional disorder" because he had once been treated as an outpatient at a mental health facility.
- A woman reported to the ACLU Privacy Project in 1975 that despite her Phi Beta Kappa college degree and her score in the top one percent on the national Medical College Admission Test, she had been turned down by thirteen separate medical schools on the ground that she had once been a voluntary patient at a New York psychiatric institution.
- A New York man reported to the Privacy Project in 1976 that he had been denied a license to drive a taxi because a credit report showed that when he was 13 years old he had been placed in a mental institution because he was an orphan and the mental hospital was the only home authorities could find for him for six months.
- A specialized medical records databank, the Multi-State Information System (MSIS), stores psychiatric records from eight states and D.C. In 1974 three patients, three doctors, and a psychiatric therapist filed suit against the New York Department of Mental Hygiene, claiming that it was using medical information from MSIS for its own files and further disseminating it.
- In a 1977 case handled by the ACLU of Maryland and the Mental Health Law Project, the Montgomery County government was forced to drop questions about civil service applicants' emotional problems, mental health treatment, use of drugs and alcohol, and "female disorders", to withdraw its blanket release form which forced applicants to authorize government access to all of their medical records, and to

pay money damages to an applicant who lost a job because she refused to answer questions she considered offensive. 1/

--In a case brought by the New York Civil Liberties Union in 1972, New York State's highest court upheld the refusal of the director of a methadone clinic to give the police photographs and other identifying data of all young black male patients in the clinic after a witness in a murder investigation claimed to have seen the killer at the clinic. The court's judgment in this case, even when there was a very strong public interest in disclosure, shows an appreciation for the paramount importance of the patient's right of privacy. 2/

--A state statute requiring physicians to report all prescriptions of certain medical drugs--including the names and addresses of patients using them--to a central, computerized, state databank was upheld in 1977 by the U.S. Supreme Court in an ACLU case, despite substantial evidence that some patients were foregoing treatment because they feared that sensitive medical information about them would be misused once it left the hands of their physicians. 3/

1/ Womeldorf v. Gleason, Civ. No. B-75-1086 (D.Md., Nov. 16, 1977).

2/ People v. Newman, 32 N.Y. 2d 379, 298 N.E.2d 651 (1973).

3/ Whalen v. Roe, 429 U.S. 589 (1977).

A Closer Look at Major Consumers of Medical Records

Having surveyed the scope of the medical privacy problem and identified some of the actual and potential abuses which result from non-medical uses of health information, I would now like to take a closer look at three major types of medical records disclosure over which patients have little or no control. These occur in (a) private and governmental insurance programs, (b) health evaluation, planning and research programs, and (c) a wide variety of governmental and private programs which have nothing to do with the delivery of health services.

(a) Private and Government Insurance Programs

Except for the professionals directly involved in the treatment of patients, insurance companies and governmental service payers are the principal users of medical records. Insurers both generate their own medical records and obtain access to medical records held by doctors and hospitals.

About 190 million Americans are protected by some form of health insurance, private or public, at an estimated cost of \$57 billion per year. Approximately 75 million people carry private disability insurance. Over 60 million are covered under workmen's compensation laws, and over 3 million receive Social Security disability payments.

An insurer's first records are gathered in establishing the individual's eligibility for coverage. To determine whether the person can be covered by a particular policy, and at what rate, the insurer will elicit extensive medical information directly from the applicant, seeking a full

description not only of his or her medical history and present physical and mental state of health, but of life style and personal habits as well. This information becomes a permanent record, often maintained in coded, computerized form, and may be referred to later when the person asks the company to consider further applications or claims. It may also be shared with other insurers, and contributed to industry-wide databanks like the Medical Information Bureau.

The applicant's own submission may not be sufficient. Under certain conditions the insurer may decide to check physicians' and hospital records, using either its own investigators or the services of an independent investigative reporting agency. The applicant has paved the way for this investigation by signing a blanket release on the application, permitting the insurer access to any and all of his or her medical records, wherever they are maintained. Because the waiver does not specify what kind of information the insurer wants, which records will be sought, or what will become of the information once it is obtained, the insurer enjoys unrestricted entry into the doctor-patient relationship.

There is growing a conviction among health care professionals that the amount of personally identifiable information solicited for the processing and review of claims is excessive. Individual doctors, especially psychiatrists, have begun to resist routine demands for the full patient record, and for some specific kinds of information. For example, in a recent

controversy noted by the Privacy Commission, the Blue Cross-Blue Shield Federal Employee Benefit Program devised a new form which required detailed descriptions of diagnosis, treatment, and prognosis with the submission of psychiatric benefit claims. The resulting outcry from doctors and patients persuaded Blue Cross-Blue Shield to modify its reporting forms. But, as the Privacy Commission remarked, the unusually sharp reaction was probably attributable to the special social stigma which attends mental and nervous disorders. Similarly detailed reports are routinely supplied for claims growing out of physical ailments. Some doctors and hospital record custodians do take the trouble to argue when they feel that the insurer's demands are too broad, but generally only when some particularly sensitive data are involved. It is a common complaint among health care professionals that insurance companies and government service payers do not tell them specifically what information is needed to process a claim. The patient, of course, has little or nothing to say about how much of the record is released; his right of privacy rests on whatever decision the doctor or hospital makes on his behalf.

The pro forma nature of patient authorization, which legitimizes the insurer's intrusion into the doctor-patient relationship as, in effect, a third partner, is the crux of many of these problems. When patients sign a blanket waiver of confidentiality, they are giving a free hand to the insurer or service payer to take whatever information it wants and to use the information as it likes. Such "consent" is not

informed, because patients do not know what is in their own records or what the insurer will do with the records, and it is not freely given, because there is no effective choice.

(b) Evaluation, Planning and Research Programs

Medical records are also used extensively for the evaluation and planning of medical services. Service payers themselves, both private and governmental, have an interest in learning how different kinds of medical facilities are utilized and in formulating model standards of utilization and treatment, such as the average length of hospital stay for a particular kind of surgery or the diagnostic tests most generally prescribed for a particular illness, as a means of controlling their costs. For all of these purposes, individually identifiable patient records may be used, and where that happens, it is almost always done without the patient's knowledge or permission, or at best, with only a perfunctory form of patient consent.

Publicly funded services are routinely monitored by agencies at all levels of government. Though one purpose is to uncover fraud and abuse--charges for services never rendered, for example--another is to assure that patients are being treated as efficiently as possible, and within generally accepted professional standards of good medical practice. The newest, most controversial mechanism for the monitoring and evaluation of government-funded health care is the Professional Standards Review Organization (PSRO), mandated by Title XI of the 1972 Social Security Act. This

statute sets up a network of local and regional bodies, composed primarily of physicians and other medical professionals, initially to review the operations of hospitals that treat Medicare and Medicaid patients, but ultimately to review all institutions involved in the delivery of publicly funded health care.

Because PSROs are only beginning to function, no one is yet sure how patients' records will be handled, or how patients' rights of privacy will be affected. But it is clear that identifiable patients' records will be disseminated beyond the hospital to be examined by people who are not a part of the primary doctor-patient relationship nor directly involved in the patient's care. The implications of PSRO's are greater than they may appear today because they may eventually be absorbed into a national health insurance system as the principal mechanism for conducting health reviews. As such, PROs would have access to the medical records of every person in the country.

The uses of identifiable medical records for research purposes are too many and too complex to be explored here in any detail. But the reassurances of unbreakable confidentiality which accompany research projects using identifiable patient records should be noted in light of those known instances in which the identity of the patients has been divulged. While the breach of confidentiality is grievance enough itself, there are even more serious grounds for objection in what the breach reveals about the uses of personal records in some

kinds of research. One case in point is a study carried out in New York State with funds from the National Institutes of Health to learn the long-term effects of abortion on the subsequent reproductive lives of 21,000 women who had abortions, as compared with 27,000 women who had live births. This apparently involved the matching of fetal death certificates with other personal, marital, and medical records in various government agencies all over the country. None of these 48,000 women had given their consent or even knew about the study. The story came to light in early 1977 when a preliminary report on the study, submitted to members of the state legislature, inadvertently revealed the names of some of the subjects.

The evolving methods of handling identifiable patient records for new research, evaluation and audit purposes has drastically changed the nature of the doctor-patient relationship. It is now a relationship routinely embracing many parties, most of whom are unknown to the patient, and certainly unauthorized by the patient. While the case has been made to justify the intervention of outside agencies to conduct reviews, planning, and research, until recently no countervailing case for patient privacy has been put forth.

(c) Non-Medical Uses

Medical information, of course, is also of interest to many agencies which are not involved, even indirectly, in the provision of health care. Employers, schools, police, courts, licensing bodies, insurers, creditors, social workers, the

press, all use medical information. Medical information is required for marriage licenses, drivers licenses, and most occupational licenses. Extensive medical information is solicited for life insurance, both directly from the applicant, and through reports compiled by investigative reporting agencies--so much information, in fact, that the life insurance industry maintains its own giant computerized databank, holding some 11 million records.

Law enforcement agencies generally assert--without much evidence--that medical records are an important investigative tool. Sometimes police efforts to obtain records are rebuffed, as in the case mentioned earlier of the New York methadone clinic whose director's refusal of a police demand for the names and photographs of the clinic's patients in a murder investigation was eventually upheld by the state court of appeals. But more informal efforts may be successful, especially since police officers are sometimes permanently stationed in large metropolitan hospitals where they may have virtually unrestricted access to the record room. Doctors and police sometimes work hand-in-hand: this happened recently in New Rochelle, New York, where the medical director of a methadone clinic showed the police commissioner the files of a woman who had brought a complaint against the police department, just before a public hearing on the complaint.

The largest non-medical users of medical information are employers. Everyone is familiar with the employment application medical form that elicits the most intimate details not only about the applicant, but also about members of his family.

In addition, the applicant must frequently sign a release permitting the employer access to his physicians' and hospital and other medical records, preparatory to a pre-employment investigative report. Medical questions, particularly relating to psychiatric history and use of drugs and alcohol, may be included in a pre-employment polygraph test. Once hired, the employee's medical condition may continue to be monitored through periodic examinations performed by a company physician. Also well known is the fact that both employment and promotion are frequently denied on highly arbitrary medical grounds--the "five-year rule" for cancer patients, for example, or a bar to the employment of anyone who has ever received psychiatric treatment.

Reconstructing a Right to Medical Privacy

It is clear, then, that medical privacy has been substantially eroded and requires a major reconstruction if it is not to disappear altogether. With so many different participants in what is anachronistically called the "doctor-patient relationship," we strongly endorse the conclusion of the Privacy Commission that a major effort must be made to develop a uniform, legislative right to privacy of medical information. We submit that this effort should be based on the following principles:

1. In acknowledgement of the inevitability that personal medical data will go beyond the immediate health care provider, patients must be given an absolute right of access to their own medical records, wherever such records exist, and they must be given a realistic right of informed consent to each and every dissemination of their medical records. Patients must be able to learn what their records contain, where they are, who will see them, and how they will be used. There must be a practical procedure for correcting inaccurate information, and for documenting the "record trail" of each individual.
2. There must be a statutorily defined expectation of confidentiality with respect to medical data no matter where such data are maintained, and patients must be able to enforce that expectation of confidentiality against every person, organization, or agency that maintains their medical records.
3. Insurers and service payers, auditors, researchers, planners and others who use medical data for health-care-related purposes must be made to re-examine their traditional methods of handling medical information, and specifically justify on the public record each use they make of personally identifiable medical records. Every effort must be made to devise new information procedures that would allow these persons and agencies to accomplish their proper functions without using identifiable data. Where this proves impossible, there must be a precise definition of the specific data that are required, and a precise procedure for limiting each user's access to those data alone and barring further dissemination.
4. Non-medical uses of medical data must be sharply curtailed. Except to the extent that such records are to be used for specifically defined and tightly circumscribed health-related purposes, medical records must not be disclosed to government agencies unless the patient authorizes such disclosure or the agency over the patient's objection, is able to demonstrate to a court a compelling law enforcement interest in obtaining the records. All other non-health related uses of medical records--by employers, credit reporting companies, insurers and others--must be strictly limited to those uses specifically authorized by the patient.

These principles are embodied to a substantial extent in H.R. 2979, the "Federal Privacy of Medical Records Act" introduced by Chairman Preyer, and to a far lesser extent in the Administration's proposed "Privacy of Medical Information Act". Since we understand that the Subcommittee's current hearings are intended principally to explore the need for legislation in this area, I will not comment in detail on either of the pending proposals. Nevertheless, I would like to conclude my testimony by identifying the issues which the ACLU regards as most important in these two proposals and indicating why we believe H.R. 2979 is a far better vehicle for legislation than the Administration's bill. I will be happy to provide the Subcommittee with our detailed comments on, and comparison of, these bills at the appropriate time.

The first major issue is patient control over the uses of medical information. The elements of patient control include (a) the right of access to medical records, (b) a right to correct demonstrably inaccurate information in the records, and (c) the patient's right to limit disclosures of information in the records outside the normal doctor-patient relationship principally to those disclosures expressly authorized by the patient.

The two proposals are relatively similar on this issue, and to a great extent they follow the recommendations of the Privacy Commission. In its chapter on medical records the Commission pointed out that "[a] main premise of a privacy protection policy is that an individual should be able to review the records made by others of information he has

divulged, or has permitted to be divulged, and to correct any errors or amend any inadequacies in them. This premise is no less important for medical records than for other types of records. . . ."^{4/} The third element of patient control--disclosure authorization--was characterized by the Commission as a response to the fact that "the medical care relationship in America today is becoming dangerously fragile as the basis for an expectation of confidentiality with respect to records generated in that relationship."^{5/} In short, there is no way for patients to protect the privacy of their communications to doctors unless they are given a substantial degree of control over the records generated by those communications. To the extent that H.R. 2979 and the Administration proposal would to varying degrees establish such a principle, they would help to curb the erosion of medical privacy.

The second major issue in both bills is disclosure without patient authorization. On this issue the proposals part company, and H.R. 2979 is far superior. The Administration proposal presents a seemingly endless catalog of permissible disclosures, many of which are not recommended by the Privacy Commission and do not have any apparent empirical justification. As a result, the Administration bill substantially undermines the principle of patient control and is unacceptable in its current form.

^{4/} Final Report, at 300.

^{5/} Id. at 306.

Each exception to patient-authorized disclosure should be subjected by the Subcommittee to a heavy burden of proof, and when an exception is established it should be carefully circumscribed so that no further disclosures can be made outside a tightly closed system. In general, this appears to be the approach taken in H.R. 2979, which by contrast with the Administration's proposal, generally limits disclosures without the patient's consent to health-related or law enforcement purposes.

While the provisions in H.R. 2979 on disclosures without patient authorization are preferable to those in the Administration's proposal, which we oppose in this area, there are several areas in which we submit that H.R. 2979 should be improved. First, the general prohibition on redisclosure of information disclosed for audit (Section 125) and health and safety (Section 126) purposes does not apply when the further disclosure is made in circumstances "involving imminent danger of serious property damage." The purpose of this exception is not clear and it should be dropped if it cannot meet the stringent burden of proof which we submit should be applied whenever a disclosure is authorized outside the principle of patient control.

A second major flaw in the authorized disclosure provisions of H.R. 2979 is the broad Secret Service and Foreign Intelligence authorization in Section 128, which makes sensitive medical records vulnerable to governmental access merely on "a written certification, signed by a supervisory official

of a rank designated by the head of the governmental authority, that the record is being sought for a legitimate Secret Service or foreign intelligence purpose." This provision is wholly at odds with the current effort of the House Intelligence Committee to draft legislative charters for federal intelligence agencies, and it would mark a substantial departure from the judicial procedures and criminal standards established for intrusive foreign intelligence investigations of U.S. persons in P.L. 95-511, 92 Stat. 1783 (Oct. 25, 1978), the Foreign Intelligence Surveillance Act of 1978. We oppose it.

The third major issue is the procedure for governmental access. Here again, H.R. 2979 follows a generally acceptable approach, while the Administration's proposal does not. The major difference between the two is over the relationship between the governmental access procedures established for bank records in the Right to Financial Privacy Act of 1978 and the procedures proposed for the handling of medical records. The Administration bill simply imports, verbatim, the Financial Privacy Act procedures, while H.R. 2979 is drafted from the premise that (a) there is a greater and more clearly recognized expectation of confidentiality in medical records than in financial information, and (b) there is a clearer and more demonstrable law enforcement investigative interest in financial information than in medical records. This premise is clearly reflected in judicial decisions on medical and bank record issues. Compare United States v. Miller, 425 U.S. 435 (1976) with People v. Newman, supra. Closely related to this premise is a larger principle underlying H.R. 2979 that in drafting privacy protection standards each category of private information should be treated on its own merits rather than subjected to standards developed for other categories of information.

In light of the peculiar sensitivity of medical records and the absence of any general law enforcement utility in the information contained in such records, it is entirely appropriate that H.R. 2979 should limit governmental access to subpoena, summons and search warrant procedures without extending authorized access to the new "formal written request" procedures of the Financial Privacy Act. Under the written request approach virtually every government agency at the federal, state and local level would be able to obtain access to medical records, even if they do not now have compulsory process authority. Another important feature of H.R. 2979 which distinguishes it from the Administration's proposal and the Financial Privacy Act is that it would require a balancing test to be used in an enforcement proceeding. Under Section 142(d)(1) the court would be obliged to grant a patient's motion to quash a subpoena or summons "if it finds that the individual's privacy interest outweighs the government authority's need for the record." This is precisely what the New York Court of Appeals did in quashing the subpoena for methadone clinic files in the murder investigation case cited earlier, People v. Newman, supra.

In our further detailed analysis of this legislation, we will propose a variety of amendments in all three of the areas I have outlined this morning in order to bring the legislation into conformity with those privacy principles which must be followed if a right of medical privacy is to be reconstructed.

Thank you for the opportunity to present our views.

Mr. PREYER. Thank you. We will be particularly interested in your testimony.

At this time the subcommittee stands adjourned.

[Whereupon, at 12:01 p.m., the subcommittee adjourned, to reconvene subject to the call of the Chair.]

PRIVACY OF MEDICAL RECORDS

THURSDAY, JUNE 14, 1979

HOUSE OF REPRESENTATIVES,
GOVERNMENT INFORMATION
AND INDIVIDUAL RIGHTS SUBCOMMITTEE
OF THE COMMITTEE ON GOVERNMENT OPERATIONS,
Washington, D.C.

The subcommittee met, pursuant to recess, at 10:07 a.m., in room 2247, Rayburn House Office Building, Hon. Richardson Preyer (chairman of the subcommittee) presiding.

Present: Representatives Richardson Preyer, Robert F. Drinan, Peter H. Kostmayer, David W. Evans, Ted Weiss, Thomas N. Kindness, and M. Caldwell Butler.

Also present: Timothy H. Ingram, staff director; Robert Gellman, associate counsel; and Thomas Morr, minority professional staff, Committee on Government Operations.

Mr. PREYER. The committee will come to order.

Since we have gone into session already this morning, I am afraid that some of our members will not be here until after the first vote or quorum call. We have quite a few witnesses today, and we will proceed.

Today, we continue hearings on legislation to protect the confidentiality of medical records. The two bills under consideration are H.R. 2979 and H.R. 3444. At earlier hearings, testimony focused on the general need for and purposes of medical privacy legislation.

We will now begin to move away from these general issues and pay more attention to the details of the bills. In this way, I hope to identify problems and find solutions to them.

To begin this morning, we will have a panel of three representatives of the Public Health Service: James Erickson, Director of the Bureau of Medical Services; Emery Johnson of the Indian Health Service; and Michael English who is with the Office of Legal Adviser at St. Elizabeths Hospital.

Thank you for joining us today. I understand each of you will have a brief opening statement and then we can go into the questions. Who would like to lead off?

Dr. Johnson?

STATEMENT OF EMERY A. JOHNSON, M.D., DIRECTOR OF THE INDIAN HEALTH SERVICE, HEALTH SERVICES ADMINISTRATION

Dr. JOHNSON. Mr. Chairman, I am Dr. Emery Johnson, the Director of the Indian Health Service. I would like to submit my statement for the record and then briefly summarize it.

Mr. PREYER. Surely.

Dr. JOHNSON. The Indian Health Service is the primary Federal health resource for approximately three-quarters of a million Indians and Alaska Native people primarily living on or near Federal Indian reservations and in traditional Indian country such as Oklahoma and Alaska.

We operate a comprehensive program with some 50 hospitals, over 100 health centers, and something in the neighborhood of 1,000 different locations where we provide health services.

In this process, as you can imagine, we have a very comprehensive and very difficult problem in maintaining large systems of records. We had last year almost 80,000 admissions, over 3 million ambulatory care visits, and we maintain about 700,000 records, in addition, in the contract facilities along with about a million and a half records in our own system.

It's been a major challenge, I think, to the program, particularly in training of our staff to understand the complexities of the law, the accounting procedures that have been required and so forth.

However, on balance, we think that the Privacy Act has had minimal effect on the Indian Health Service's operations. We have had a long history of concern for the confidentiality of our patients' records. We are basically a medical care institution and we have always had this patient-physician medical record, the sense of confidentiality.

We are interpreting the law, I think, somewhat differently perhaps in that we by policy have not set up two different methods of access to the records. We have taken a position that a medical record is in its nature a complex document.

It has many initials and shorthand notations and so forth that, for many patients, would tend to be confusing and not easily understood. And so, in our program, we routinely have a health professional available to assist the patient in reviewing the record.

That does take a little extra health professional time, but we think it improves the quality of the review by the patient and certainly opens up the access and eliminates any possible concerns that there may be dual ways in which patients can get access to the records.

Mr. PREYER. You make the entire record available to the patient?

Dr. JOHNSON. That is right. We provide the health professional to sit down with the patient and the record and they can go over it together and the patient can ask questions of the physician, nurse, record librarian, whoever may be most appropriate to sort out the linkages between the various parts of the record.

Mr. PREYER. Have you had a lot of requests from patients to review their records?

Dr. JOHNSON. No. We have had a very small number. I think the highest number we ever had was about 700. I think last fiscal year, 1978, we had 638. The first quarter of this year, we have had about 158, as I recall. So, it is certainly not a major burden to the staff.

As I said earlier, I think the major burden has been the administrative accounting for disclosure procedures where whenever you send a record to someone else, you have to make some kind of a notation.

That does take a great deal of time. But, it has not been an overwhelming burden. I feel that this is a limiting factor.

I guess in summary, Mr. Chairman, we have found the act to be a very positive experience. I think the patients have recognized their right to access and because they have access, they have had less concern as to what is really there.

Mr. PREYER. Thank you, Mr. Johnson. We appreciate it.

[Dr. Johnson's prepared statement follows:]

PREPARED STATEMENT BY EMERY A. JOHNSON, M.D., DIRECTOR OF INDIAN HEALTH
SERVICES, HEALTH SERVICES ADMINISTRATION

Mr. Chairman, and members of the subcommittee on Government Information and Individual Rights, I appreciate the opportunity to speak to you of our experiences with our medical record systems under the Privacy Act. The Indian Health Service (IHS) is the primary Federal health resource for approximately 760,000 Indians and Alaska Native people primarily living on or near Federal Indian Reservations or in traditional Indian country such as Oklahoma and Alaska. The Indian Health Service provides direct health services through 50 hospitals, 101 health centers (including 21 school health centers) and several hundred other health clinics.

Supplemental health and medical care services are provided through contractual arrangements with various health care providers. These contractual agreements for health services are entered into with private and community hospitals, private physicians, clinics, dentists, and providers of ancillary health services. IHS maintains such contracts with over 500 private and community hospitals, with 20 State and local health departments, and with over 1,000 physicians, dentists, registered nurses, and other health care providers.

The Indian Health Service is divided administratively into 12 Area/Program Offices. These are further divided into 96 local administrative units known as Service Units. Most Service Units encompass an IHS hospital or health center. The IHS Headquarters Office, each Area/Program Office and each Service Unit has a designated Privacy Act Coordinator.

In fiscal year 1978 there were about 112,000 hospital admissions, of which approximately 77,000 were to IHS hospitals and about 35,000 were to contract care facilities. Also during fiscal year 1978 there were about 3.1 million outpatient visits to IHS hospitals and field clinics and an additional 261,000 ambulatory visits to contract care facilities. The Indian Health Service maintains an estimated 1.5 million patient records, both active and inactive; and another 700,000 records are maintained at contract facilities. Administering the Act within such a diverse organization has been a real challenge. For example, providing adequate and consistent training to employees who work with patient records at the operating level alone requires a major effort. This activity will continue to be significant because of the continuing refinements in Privacy Act interpretations and guidance and because of normal personnel turnover.

The Indian Health Service has had a long history of concern for the confidentiality of medical data. The tradition of physician-patient confidentiality has always been of importance in the management of patient data in the delivery of health care operations of the Indian Health Service. The Privacy Act has had a minimal effect on patient access, on IHS hospital and clinical operations, and on patient welfare. The number of requests to access medical records is relatively low (648 in 1978). This is consistent with the experience of previous years. During the first quarter of 1979 there were 158 access requests by

Patients or their representatives (See Attachment A). No patients or their representatives were denied access to their records from 1975 through first quarter of 1979.

The Indian Health Service does not have cost estimates for implementation of the Privacy Act. The Act did not require the maintenance of cost estimates. It is difficult to prepare such an estimate because personnel at various levels involved in the administration of the Act are involved with other administrative activities as well as the delivery of health care.

Privacy Act training was provided and is continuing to be provided to a wide variety of people such as physicians, nurses, medical records administrators and technicians, tribal contractors, etc. Some of our facilities have modified their working and storage arrangements to improve record security. The major thrust has been to implement the Act with the least amount of disruption to our ongoing operation.

Upon implementing the Privacy Act we thought it was undesirable to establish two different methods of patient access - direct access where disclosures would not have an adverse effect on the individual and indirect access where disclosures would have an adverse effect. We believed that the employment of one uniform approach would provide a balance between ease, simplicity, and understanding by the individual seeking access, at the same time, removing any feeling of unequal treatment between direct and indirect access. Furthermore, patients who reviewed

their records did not always understand the contents of the medical record. Medical records contain technical terms, short notes and unfamiliar abbreviations. Therefore, when access was requested, if feasible, a health provider would review the medical record with the subject individual to reduce misinterpretation of record content. This approach has been helpful to these patients. While the time spent by the health care provider in this activity has been minimal because of the small number of access requests, this activity does infringe upon the provider's time in direct services.

There continues to be a substantial administrative problem in accounting for disclosures. The accounting must include the nature and purpose of each disclosure and the name and address of the person or entity to whom the disclosure is made. The number of disclosures of parts of or total patient records that must be made in the normal course of hospital and clinic operations is sizable. The list of routine uses for IHS Health and Medical Records System (Attachment B) gives some idea of the number of types of disclosures that can be made. The disclosures for purposes such as continuity of care, obtaining benefits for patients, and clerical and data processing services are typically high volume, requiring much work to keep the required accounting.

As per Department regulations, our contracts require the contractor to abide by the Privacy Act when the contractor maintains on behalf of the Department medical records [or a system of records]. IHS contract health care providers are

required to maintain an accounting of disclosures. Even though we have incorporated the appropriate language in contracts, it is difficult to assure the maintenance of accountability on the part of the contractors when disclosing information to parties other than IHS.

Another area of administrative difficulty is informing the patient about the Privacy Act where a language barrier exists. Written statements must be supplemented by the services of an interpreter. This necessarily adds time to the admission and outpatient encounter processing.

In conclusion, we have had a positive experience with the Privacy Act. A lot of administrative work was required and some changes were necessary. Basically the Act did codify and require a lot of practices that were already in effect in IHS. I have tried to describe some of the special problems that were experienced while complying with the Act. IHS operates over an extremely wide geographic area which is generally rural and remote, and serves populations with unique cultures and different languages.

ATTACHMENT A

Requests for Access to IHS Health and Medical Records System
1975 - 1978 and First Quarter of 1979

<u>Type of Request</u>	<u>First Quarter of 1979</u>	<u>1978</u>	<u>1977</u>	<u>1976</u>	<u>1975</u>
Requests for access	158 1/	648	700 2/	695	57
Requests for correction	18	91	4	3	NC
Requests denied	0	0	0	0	0

NC- Not collected.

1/ One request for access in process.

2/ Estimates - New Privacy Act reporting form used in 1977 caused confusion in use of term "access".

ATTACHMENT B

09-15-0019

System name: Health and Medical Records Systems.
HEW/HSA/IHS.

Security classification: None.

System location: Indian Health Service Service Units, Area and Program Offices, and Regional Federal Records Centers.

Categories of individuals covered by the system: Individuals examined/treated at Indian Health Service facilities, and by contract providers including hospitals, physicians, and other health providers.

Categories of records in the system: Health and medical information including examination, diagnostic and treatment data, information for proof of eligibility, social data, disease registers, commitment registers, communicable diseases, special program and/or discipline patient profiles and research studies, statistical summaries, correspondence, etc.

Authority for maintenance of the system: Public Health Service Act Section 321 (42 U.S.C. 248), 42 U.S.C. 2001; Self Determination Act (25 U.S.C. 450); Indian Sanitation Facilities Act (42 U.S.C. 20040); Synder Act (25 USC 13), Health Care Improvement Act (25 USC 1601); and Construction of Community Hospitals (25 USC 2005).

Routine uses of records maintained in the system, including categories of users and the purposes of such uses:

Records in part or total may be disclosed:

To state, local or other authorized organizations which provide health services to American Indians and Alaskan Natives for the purpose of planning for or providing such services; billing third parties for the payment of care, and reporting results of medical examination, care and treatment.

To individuals and organizations deemed qualified by the Secretary to carry out specific research solely for the purpose of carrying out such research. (42 CFR Part 5b, Appendix B, item (101))

To federal and non-federal school systems which serve American Indian and Alaskan Native children for the purpose of student health maintenance and to the Bureau of Indian Affairs and their contractors for the identification of American Indian and Alaska Native handicapped children in support of P.L. 94-142, the Education for All Handicapped Children Act of 1975.

To organizations deemed qualified by the Secretary to carry out quality assessment, medical audits or utilization review. (42 CFR Part 5b, Appendix B, item (102))

To authorized organizations or individuals for conduct of analytical and evaluation studies sponsored by the Indian Health Service.

To a Congressional office in response to an inquiry from that office made at the request of the subject individual.

Information regarding the commission of crimes or the reporting of occurrences of communicable diseases, child abuse, births, deaths, alcohol or drug abuse, etc. as may be required to be disclosed by health providers and facilities generally by the law of the State in which the facility is located. Such disclosures of information pertaining to an individual treated or referred for treatment of alcohol or drug abuse will be limited in compliance with the restrictions of the Confidentiality of Alcohol and Drug Abuse Patient Records Regulations, 42 CFR, Part 2.

In the event of litigation where one of the parties is (a) the Department, any component of the Department, or any employee of the Department in his or her official capacity; (b) the United States where the Department determines that the claim, if successful, is likely to directly affect the operations of the Department or any of its components; or (c) any Department employee in his or her individual capacity where the Justice Department has agreed to represent such employee, the Department may disclose such records as it deems desirable or necessary to the Department of Justice to enable that Department to effectively represent such party, provided such disclosure is compatible with the purpose for which the records were collected.

Policies and practices for storing, retrieving, accessing, retaining, and disposing of records in the system:

Storage: File folders, ledgers, card files, microfiche, microfilm, computer cards and tapes, and automatic or open shelf files, automated tapes and disc files.

Mr. PREYER. Dr. Erickson.

STATEMENT OF DR. JAMES H. ERICKSON, DIRECTOR, BUREAU OF MEDICAL SERVICES, PUBLIC HEALTH SERVICE

Dr. ERICKSON. Thank you, Mr. Chairman and members of the committee.

I am Director of the Bureau of Medical Services, which has the responsibility for the health care of several groups of Federal beneficiaries such as merchant seamen on active duty, commissioned officers of the Public Health Service and the National Oceanic and Atmospheric Administration, active duty members of the U.S. Coast Guard, and other Federal beneficiaries such as uniformed services active duty personnel, dependents, and retirees.

In our Bureau, we have three systems of records which contain medical records. Two of these systems involve the Division of Federal Employee Occupational Health: One is a manual system of records containing medical records of Federal employees who seek care in our Federal employee health units; the other actually is a computerized duplicate of the manual system.

Comments that I would offer today in summary—and I will also submit my full statement for the record—

Mr. PREYER. Without objection, the witness' testimony and all of our witness' statements will be made a part of the record in full.

Dr. ERICKSON. Thank you, Mr. Chairman.

We will refer to the third system of records which are patient medical records located throughout our network of hospitals and outpatient clinics.

Just as Dr. Johnson has spoken about with the Indian Health Service, there are more than 6 million medical records located in our eight general hospitals; one speciality hospital, the National Hansen's Disease Center in Carville, La.; and 27 freestanding outpatient clinics.

During fiscal year 1978, we had approximately 33,000 inpatient admissions and almost 2 million outpatient visits at our hospitals and clinics. Our hospital and outpatient clinic records are considered a single record system under the Privacy Act.

A medical record is established for each patient at each facility where he or she receives care. No distinction is made between outpatient and inpatient records.

Even before the passage of the Privacy Act of 1974, we had always been concerned about the confidentiality of our medical records and had maintained strict control over them.

So, when the act was passed and we implemented it, the transition was reasonably smooth. Initial activities were to develop Bureau guidelines for complying with the act, methods for gathering statistics regarding Privacy Act activities and so on, and the training of health personnel in the handling of records that were controlled by the Privacy Act.

The main thrust of the Privacy Act activity in the last year has simply been to insure an ongoing update and interpretation of the law by the Bureau and its components.

The Privacy Act does require that individuals be able to see and copy their records. As you know, this has not posed an insurmountable problem to us. We have used intermediaries when it has been

felt by the responsible health professional that there might be some difficulty with interpretation of the medical record or giving it directly to the patient, although much of this, as with Dr. Johnson, has been taken care of by one or another of the health professionals dealing directly with the patient with the medical record in front of them.

There have been few instances in which the record has had to be provided through an intermediary. Requests for access to our medical records have increased over 500 percent since 1976.

For example, in fiscal year 1976, there were 1,577 requests for access which increased to 10,429 in fiscal year 1978. Of these latter requests in 1978, 9,973 individuals also requested copies of their records. This represents in the last fiscal year, that is, 1978, approximately 1 request per 100 patient encounters which means 1 percent.

This large increase I think can probably be attributed to our beneficiaries' growing awareness of the fact that the Privacy Act exists and what they can ask for and what they can see. It has not been, however, an insurmountable burden to us to take care of this.

We have also received 26 requests for either amendment or correction of some portion of the medical record. Most of these have been resolved at the local hospital and clinic level. We have had only one request for amendment of a record which was appealed to the Assistant Secretary of Health.

A couple of requests we had which were denied at the local hospital level were later granted at the Bureau level. They were such things as expressing a medical opinion in a nonprejudicial manner and another one to correct an identifier for the patient.

So, this has not posed a problem to us. Disclosure restrictions of the act also, we feel, have not interfered with patient care and other necessary uses of records because the routine use provisions enabled us to use the records without patient consent when necessary.

Present law does have flexibility for disclosure to third parties, and we feel that it is an effective mechanism for permitting essential disclosures. For example, one of our primary beneficiary groups is the Coast Guard.

If transfer of a member's records from a PHS facility to the Coast Guard would require patient consent in each case, the provision of health care would certainly be impaired if the service member chose not to consent to disclosure.

It certainly is necessary, in our belief, to maintain vigilance over the control of our medical records and we have always been concerned about confidentiality.

We feel that a patient certainly should have the right to access and to check the accuracy of his or her record's information.

In my judgment, we have faced no insurmountable problems as the Privacy Act became operational in the Bureau of Medical Services. It served to reinforce our longstanding commitment to protect the privacy of our patients and their own records.

Thank you very much, Mr. Chairman.

Mr. PREYER. Thank you, Dr. Erickson.

[Dr. Erickson's prepared statement follows:]

PREPARED STATEMENT OF JAMES H. ERICKSON, M.D., M.P.H., DIRECTOR, BUREAU
OF MEDICAL SERVICES, HEALTH SERVICES ADMINISTRATION

Mr. Chairman and Members of the Committee:

Thank you for inviting me to speak to you today regarding the protection of the confidentiality of medical records. I am the Director of the Bureau of Medical Services, which has the responsibility for the health care of merchant seamen on active duty, commissioned officers of the Public Health Service and the National Oceanic and Atmospheric Administration, active duty members of the U.S. Coast Guard, and other Federal beneficiaries, such as uniformed services active duty personnel dependents and retirees. In addition, our role has become more diversified through the years as we have become involved with local community medical needs, as part of the overall mission of the Public Health Service and the Health Services Administration.

The Bureau of Medical Services is responsible for three systems of records which contain medical records. Two of these systems involve the Division of Federal Employee Occupational Health: one is a manual system of records containing medical records of Federal employees who seek care in our Federal Employee Health Units; the other actually is a computerized duplicate of the manual system. My comments today will specifically refer to the third system of records which are patient medical records located throughout our network of hospitals and outpatient clinics. There are more than 6 million medical records located at our eight general hospitals; one specialty hospital, the National Hansen's Disease Center in Carville, Louisiana; and 27 freestanding outpatient clinics. During fiscal year 1978 we had approximately 33,000 inpatient admissions and 1,725,000 outpatient visits at our hospitals and clinics. Our hospital and outpatient clinics records are considered a single

record system under the Privacy Act. A medical record is established for each patient at each facility where he or she receives care. No distinction is made between outpatient and inpatient records.

Even before the passage of the Privacy Act of 1974, the Bureau of Medical Services had maintained strict control over the confidentiality of its medical records. Therefore, when we had to implement the Act, the transition was reasonably smooth. The initial activities required were the development of Bureau guidelines for complying with the Privacy Act, installation of additional safeguards, and the development of methods for gathering statistics regarding Privacy Act activities. In addition, we had to train personnel working with records controlled by the Privacy Act. All other personnel were briefed regarding their rights and responsibilities under the Privacy Act.

The development of policies and procedures for maintaining and processing data subject to the Privacy Act has been essentially stabilized during the past year. Therefore, the main thrust of our Privacy Act activity during the past year has been to insure an ongoing update of the interpretation and application of the law by the Bureau and its components.

Let me first discuss the problems connected with release of the medical record to the patient. The Privacy Act requires that individuals be able to see and copy their records, but recognized that it may not always be advisable to provide the record directly to the person. Our regulations implementing the Act require that a person requesting a record designate a third party through whom the record will be channeled should the

releasing official believe that direct access would be likely to have an adverse effect on the person. There have been relatively few instances in which the record has had to be provided through the intermediary. In some instances individuals who have been diagnosed as emotionally unstable have objected to naming an intermediary and have threatened our personnel, but this has been dealt with effectively by having a staff member - a health professional - interpret the record to the patient, thus acting, in effect, as the intermediary. Interpretation of the record is not always an ideal solution, because the designated person may not be qualified to interpret the data. It hasn't been an easy task to develop an approach that assures the patient's rights and at the same time assures that the record will be interpreted properly. Patients have exercised their rights under this provision.

Requests for access* to our medical records has increased over 500% since 1976.² In FY 1976 there were 1,577 requests for access which increased to 10,429 requests in FY 1978. Of these latter requests, 9,973 individuals also requested copies of their records. This large increase can probably be attributed to our beneficiaries growing awareness of the Privacy Act.

Since the implementation of the Act, we have received 26 requests for either the amendment of or correction of some of our medical records. Most of these requests have been resolved at the hospital or clinic level. We have had only one request for an amendment of a record which was denied by the Assistant Secretary for Health following an appeal.

*Either for subject review or copies of records.

This denial involved a request to expunge a portion of a medical record which included material that might be needed later to determine the legal rights of the government or the patient. Two requests for amendment to the records which were denied at the hospital level were later granted at the Bureau level. One request concerned the method of expressing a medical opinion in a nonprejudicial manner and the other was to correct the race-identifier of a patient.

There have been no precise government-wide guidelines for accounting for the costs of the Act. We did prepare an estimate pursuant to OMB direction, including the cost of start-up and one year of operation. We have applied the same criteria provided by OMB to the succeeding years. Thus, our figures give some indication of the cost of implementing the Act, but they are rough estimates.³ Our costs of implementing the Privacy Act were absorbed through the resources of various programs.

The period of September 1975 to September 1977 represented the formula-tive phase of the operation and maintenance of the Privacy Act. We experienced costs of approximately \$228,000 per year. Fiscal year 1978 reflected a drop of about \$43,000 from the previous years. This is due to operating efficiencies developed during the implementation phase. Based on six months of data for fiscal year 1979, we may expect to spend approximately \$186,000 this fiscal year to maintain Privacy Act activities in the Bureau. These cost figures (if maintained) will approximate those of FY 1978.

Our major problems in determining whether a record may or may not be disclosed to third parties concern the following issues: records of minors, and records of health care that involve sensitive medical problems such as venereal disease or pregnancies. Although the Privacy Act does address medical records specifically, there is medical information about individuals contained in other records which is not retrieved by name and therefore does not fall under the control of the Privacy Act.

Disclosure restrictions of the Act have not interfered with patient care and other necessary uses of records, because the routine use provisions have enabled us to identify and make disclosures, without patient consent, for various purposes compatible with the basic treatment purpose of the record. Stricter requirements that would have necessitated patient consent would have resulted in overly broad, and therefore, meaningless consent forms in many situations. This would have made the administration of the Act much more complex and might possibly have hindered or delayed some health care. I believe that judiciously drawn provisions* for disclosure without patient consent can protect patients' rights while permitting necessary disclosures. The present law does have flexibility for disclosure to certain third parties, and we feel that it is an effective mechanism for permitting essential disclosures. For example, one of our primary beneficiary groups is the Coast Guard. If transfer

*Some examples of routine uses for BMS Patient Medical Record System allow for disclosures to: health organizations, government agencies, private physicians for results of physical examinations, treatment or care provided by BMS, to the Bureau of Prisons, NOAA, OWCP; congressional offices on behalf of a constituent, contractor for refining of records, and Department of Justice to defend the Government.

of a member's records from a PHS facility to the Coast Guard would require patient consent in each case, the provision of health care would certainly be impaired if the service member chose not to consent to disclosure. There are occasions where an individual may refuse to sign a consent for disclosure even if it is to his or her benefit.

I have a few observations beyond the remarks I have already made on routine uses and their implications for this proposed legislation. Any proposed legislation should address both the formal "medical record" as well as other clinical information in health care facilities. Thus, consideration should be given to clarifying the definitions of "medical record" and "clinical information." In addition, any proposed legislation should include outpatient records in Federal facilities. As I read H.R. 2979, I am concerned that it does not include outpatient records. We could not implement this proposed legislation without changing our present medical record system, which maintains a unit medical record containing inpatient and outpatient records for each patient at each of our facilities where he or she received care.

Once the initial impact of implementing the Privacy Act into our management program was established, maintenance became a routine function of record management. It is necessary to maintain vigilance over the control of medical records. A patient should have the right to access and to check the accuracy of information in his or her own record. The foundation for our control of the availability of clinical information was based on Part I of the PHS regulation, "Availability of Records and Information." Thus, in my judgment, we faced no insurmountable problems as the Privacy Act became operational in BMS. It only served to reinforce our longstanding commitment to protect the privacy of our patients and their medical records.

REFERENCES

1. Attachment 1 - A complete listing of all BMS systems of records. Attachment 2 is a copy of the system notice for the Patient Medical Records of the Division of Hospitals and Clinics.
2. Attachment 3 - A table of annual Privacy Act workload statistics. In CY 1976 we had 1,577 requests for access, in CY 1977 there were 6,935 requests, and in CY 1978 there were 10,429. Including the first quarter of CY 1979, we have received a total of 22,893 requests for access since the implementation of the Act in 1975.

Rate of change in access:	1976 versus 1977	339.8%
	1976 versus 1978	561.3%
3. Attachment 4 - The data for the incremental cost of implementing the Privacy Act was based on criteria developed for an OMB study in 1976. Each category is discussed below:
 1. Publications Requirement: This includes costs of printing and distributing BMS Circulars providing Privacy Act guidance to Headquarters and field components, reference materials, and other related administrative printing.
 2. Training: This cost figure includes initial training of management personnel, in-house training, interagency training, and various training aids.
 3. Granting Access: This was computed on a predetermined salary average commensurate with an estimated amount of personnel time spent on this activity. It also includes the approximate cost of duplicating copies of the record requested by the subject individual. We normally do not charge an individual for a copy of their record unless the total cost of duplication amounts to \$25.00 or more.
 - 4 and 6: Correction of Records, Accounting and Disclosures: This is based on a predetermined salary average and an equivalent time spent on these activities.
 5. Security Control: This included costs of shredders, new locking file cabinets and installation of locked secure areas.
 7. New Data Collection Procedures - We have not developed new collection procedures to comply with the Privacy Act.
 8. All Other Costs: This includes the salary of all personnel officially assigned to administer the Privacy Act activities in Headquarters and in the field.

Privacy Act Record Systems
Bureau of Medical Services
and
USCG Military Personnel Health Record System

The following systems of records cover information controlled by the Bureau of Medical Services. The records in the referenced Coast Guard system include those individuals who are Coast Guard personnel and have been treated by PHS health care providers. - The Coast Guard records are under the control of the Department of Transportation.

<u>Number</u>	<u>Name of System of Records</u>	<u>System Manager</u>
09-15-0001	Division of Federal Employee occupational health - Employee Health Records	Director, Division of Federal Employee Occupational Health
09-15-0002	Record of Patients Personal Valuables and Monies	Chief, Financial Management Branch, DMS
09-15-0003	Contract Physicians and Consultants	Chief, General Service Branch, DMS
09-15-0004	Federal Employee Occupational Health Data System	Director, Division of Federal Employee Occupational Health
09-15-0005	Dental Research - Evaluation of Restorative Materials	Director, USPHS Hospital, San Francisco, California/ATTENTION: Research Coordinator
09-15-0006	Cooperative Research Studies - Coronary Artery Disease	Director, Division of Hospitals and Clinics
* 09-15-0007	Patients Medical Record System PHS Hospitals/Clinics	Director, Division of Hospitals and Clinics
09-15-0008	Emergency Non-PHS Treatment Authorization File	Director, Division of Hospitals and Clinics

*Medical Record System that is the focus of the June 14, 1979 testimony.

Attachment 1

<u>Number</u>	<u>Name of System of Records</u>	<u>System Manager</u>
09-15-0009	Cooperative Research Services System - Pyelonephritis	Director, Division of Hospitals and Clinics
09-15-0010	Cooperative Research Studies System - Essential Hypertension	Director, Division of Hospitals and Clinics
09-15-0022	Accounts Receivable	Chief, Financial Management Branch, BMS
09-15-0028	PHS Clinical Affiliation Trainee Records	Director, Division of Hospitals and Clinics
09-15-0029	PHS Beneficiary - Contract Medical/Health Care Records	Director, Division of Hospitals and Clinics
09-15-0034	Health Care Provider Profile	Director, Division of Hospitals and Clinics
DOT/CG 572	USCG Military Personnel Health Record System	Chief, Office of Health Services Department of Transportation U.S. Coast Guard Headquarters

44304

NOTICES

09-15-0007

System name: Patients Medical Record System PHS Hospitals/Clinics HEW/HSA/BMS.
Security classification: None.

System location: See appendices 1 and 2 and Regional Federal Records Center.

Categories of individuals covered by the system: Individuals examined/treated at Public Health Service Hospitals and Clinics.

Categories of records in the system: Medical examination, diagnostic and treatment data, information for proof of eligibility, social data, disease registers, treatment logs, statistical summaries, correspondence.

Authority for maintenance of the system: Public Health Service Act, Section 321 (42 U.S.C. 248).

Routine uses of records maintained in the system, including categories of users and the purposes of such uses:

Disclosure may be made to: (1) any community health organization, government agency, private physicians and/or company which had requested or arranged for an examination, treatment or care of an individual by the Bureau of Medical Services; (2) Navy, Air Force for reports of uniformed service personnel and their dependents examination/treatment; (3) Coast Guard for reports of uniformed service personnel and their dependents; (4) and for reports of American seamen found to be suffering from conditions that render them hazardous to themselves or to others aboard ship; (5) NOAA for reports of uniformed service and other personnel of that agency; (6) INS for reports of aliens examined and treated for and in behalf of that agency; (6) Bureau for Prisons for reports of examination and treatment of patients examined and/or treated for and on behalf of the UP; (7) Department of Health or other agency of a state or its subdivision for reports required under state law or regulation; (8) U.S. Department of Labor, Office of Workers Compensation Programs, for persons claiming compensation benefits due to personal injury while employed by the government; (9) Health professions students serving an affiliation at the institution and Non-agency physicians or laboratories for continued care of the patient; (10) Veterans Administration to assist uniformed service personnel, retirees and veterans obtain medical care or benefits.

Disclosure may be made to a congressional office from the record of an individual in response to an inquiry from the congressional office made at the request of that individual.

The Department contemplates that it will contract with a private firm for the purpose of collating, analyzing, aggregating or otherwise refining records in this system. Relevant records will be disclosed to such a contractor. The contractor shall be required to maintain Privacy Act safeguards with respect to such records. (42 CFR Part 5b, Appendix B, item (9)).

Disclosure may be made to individuals and organizations, deemed qualified by the Secretary to carry out specific research solely for the purpose of carrying out such research. (42 CFR Part 5b, Appendix B, item (10)).

Disclosure may be made to organizations deemed qualified by the Secretary to carry out quality assessment, medical audits or utilization review. (42 CFR Part 5b, Appendix B, item (102)).

Information regarding the commission of crimes or the reporting of occurrences of communicable diseases, child abuse, births, deaths, alcohol or drug abuse, etc. as may be required to be disclosed by health providers and facilities generally by the law of the State in which the facility is located. Such disclosures of information pertaining to an individual treated or referred for treatment of alcohol or drug abuse will be limited in compliance with the restrictions of the Confidentiality of Alcohol and Drug Abuse Patient Records Regulations. (42 CFR, Part 2).

In the event of litigation where one of the parties is (a) the Department, any component of the Department, or any employee of the Department in his or her official capacity; (b) the United States where the Department determines that the claim, if successful, is likely to directly affect the operations of the Department or any of its components; or (c) any Department employee in his or her individual capacity where the Justice Department has agreed to represent such employee, the Department may disclose such records as it deems desirable or necessary to the Department of Justice to enable that Department to effectively represent such party, provided such disclosure is compatible with the purpose for which the records were collected.

Policies and practices for storing, retrieving, accessing, retaining, and disposing of records in the system:

Storage: File folders, magnetic tape, punch cards, microfilm.
Retrievability: Purpose: communication for patient care by health care team and related personnel. Administrative use for facility management and medical care evaluation, by medical and related staff, administrative staff of the facility. Educational uses to educate and train medical and allied health personnel. Research, study of disease cause, treatment and methods of care delivery. Users: health care team, other medical and allied medical personnel. Medical and allied health students. Administrative personnel for determination of eligibility for care and facility management. Reports of examination/treatment of individuals at request of DHEW-OP, CPD. Reports of adverse drug reaction and medical device malfunction to FDA. Recover cost of care - PHS Claims Officer. Retrievability: indexed by name, register number, number control register, disease and operation, uniformed services service number which is the social security number. Those records indexed by SSN are retrieved in accordance with 7 (a) (2) (B) of the Privacy Act.

Attachment 2

Safeguards: Locked storage area, personnel training and instruction, PHS Policy on release of information, job description responsibility for individual employees. For computerized records, safeguards established in accordance with Department standards and National Bureau of Standards guidelines (e.g. security codes) will be used, limiting access to authorized personnel.

Retention and disposal: Numbers of years held at HSA (since 1970 - 5 years after last activity. Number of years held at Federal Record Center before disposal - 50 years active duty uniformed service personnel, 35 years all others. Microfilmed records prior to 1970 - permanent. How destroyed: According to FRC policy.

System manager(s) and address:

Director, Division of Hospitals and Clinics
Federal Center Building 01, 6525 Belcrest Road
Hyattsville, Maryland 20782

Notification procedure: Same as system location, but not including Regional Federal Records Centers. Individual must contact appropriate facility directly. An individual who requests notification of or access to a medical/dental record shall, at the time the request is made, designate in writing a responsible representative who will be willing to review the record and inform the subject individual of its contents at the representative's discretion. (These notification and access procedures are in accordance with Department Regulations (45 CFR, Section 5b.6) Federal Register, October 8, 1975, page 47411.)

Record access procedures: Same as notification procedures. Requesters should also reasonably specify the record contents being sought. (These access procedures are in accordance with Department Regulations (45 CFR, Section 5b.7) Federal Register, October 8, 1975, page 47411.)

Contesting record procedures: Contact the official at the address specified under notification procedures above, and reasonably identify the record and specify the information to be contested. (These procedures are in accordance with Department Regulations (45 CFR, Section 5b.7) Federal Register, October 8, 1975, page 47411.)

Record source categories: Individual, health care personnel, other hospitals and physicians, employers, social agencies, maritime unions, shipping companies.

Systems exempted from certain provisions of the act: None.

Appendix 1

Director, USPHS Hospital
3100 Wyman Park Drive
Baltimore, Maryland 21211

Director, USPHS Hospital
77-Warren Street
Boston (Brighton), Massachusetts 02135

Director, USPHS Hospital
4400 Avenue N
Galveston, Texas 77550

Director, USPHS Hospital
210 State Street
New Orleans, Louisiana 70118

Director, USPHS Hospital
6500 Hampton Boulevard
Lynchmont
Norfolk, Virginia 23508

Director, USPHS Hospital
15th Avenue and Lake Street
San Francisco, California 94118

Director, USPHS Hospital
Box-3145 or
1131 14th Avenue South
Seattle, Washington 98114

Director, USPHS Hospital
Bay Street and Vanderbilt Avenue
Staten Island, New York 10314

Director, USPHS Hospital
Carville, Louisiana 70721

Appendix 2

Director
USPHS Outpatient Clinic
1600 Clifton Road, N.E.
Atlanta, Georgia 30333

Director
USPHS Outpatient Clinic
50 High Street, R. 609
Buffalo, New York 14203

Director
USPHS Outpatient Clinic
314 Federal Building
334 Meeting Street
Charleston, S. C. 29403

Director
USPHS Outpatient Clinic
1439 S. Michigan Avenue
Chicago, Illinois 60605

Director
USPHS Outpatient Clinic
P. O. and Courthouse Building
5th and Walnut Street
Cincinnati, Ohio 45202

Director
USPHS Outpatient Clinic
New P. O. Building, West 216 3rd Street and Prospect Ave.
Cleveland, Ohio 44113

Director
USPHS Outpatient Clinic
14700 Riverside Drive
Detroit, Michigan 48215

Director
USPHS Outpatient Clinic
Box 1410 or
991 Ala Moana Boulevard
Honolulu, Hawaii 96807

Director
USPHS Outpatient Clinic
304 U. S. Customs Building
701 San Jacinto Street
Houston, Texas 77002

Director
USPHS Outpatient Clinic
Box 4704 or Room 324
Post Office Bldg
111 West Monroe Street
Jacksonville, Florida 32201

Director
USPHS Outpatient Clinic
969 Madison Avenue
Memphis, Tennessee 38104

Director
USPHS Outpatient Clinic
41 S. W. 1st Avenue, Room 712
Miami, Florida 33130

Director
USPHS Outpatient Clinic
125 Federal Building
Mobile, Alabama 36602

Director
USPHS Outpatient Clinic
245 West Houston Street
New York, New York 10014

44388

Director
USPHS Outpatient Clinic
Room 700
US Customs House
2nd & Chestnut Sts
Philadelphia, Pa. 19106

Director
USPHS Outpatient Clinic
U. S. Post Office and Courthouse
7th Avenue and Grant Street
Pittsburgh, Pa. 15219

Director
USPHS Outpatient Clinic
209 Federal Office Building
5th Street and Austin Avenue
Port Arthur, Texas 77640

Director
USPHS Outpatient Clinic
331 Veraoda Street
Portland, Maine 04103

Director
USPHS Outpatient Clinic
220 Courthouse
Broadway and Main Street
Portland, Oregon 97205

Director
USPHS Outpatient Clinic
1520 Market Street
St. Louis, Missouri 63103

Director
USPHS Outpatient Clinic
2105 Fifth Avenue
San Diego, California 92101

Director
USPHS Outpatient Clinic
Box 3788
or 8 1/2 Fernandez Juncos Avenue
San Juan, Puerto Rico 00904

Director
USPHS Outpatient Clinic
Box 831
or 825 S. Beacnn Street
San Pedro, California 90731

Director
USPHS Outpatient Clinic
P. O. Box 9625
or 1602 Drayton Street
Savannah, Georgia 31402

Director
USPHS Outpatient Clinic
P. O. Box 1611
or 601 Florida Avenue
Tampa, Florida 33601

Director
USPHS Outpatient Clinic
Switzer Bldg.
4th and C Streets, S.W.
Washington, D. C. 20201

Privacy Act
Workload Statistics

	Sept. 1975 Dec. 1975	CY 1976	CY 1976	CY 1977	Jan. 1979 Mar. 1979
A. Requests for Access	878	1577	6935	10,429	3074

All requests for access were granted either to the patient directly or through a designated third party.

B. Requests for Amendment	3	7	4	9	3
------------------------------	---	---	---	---	---

All amendments were approved except one which was a request to expunge a portion of a medical record. The appeal was denied by the Assistant Secretary for Health and Surgeon General.

C. Access Provided					
In person:	304	1027	3685	4879	1631
By copy	617	1495	6643	9973	2661

Attachment 3

PRIVACY ACT OF 1974
 INCREMENTAL COST OF IMPLEMENTATION
 PATIENT MEDICAL RECORDS
 09-15-0007

Division of Hospitals and Clinic
 Bureau of Medical Services

	Start- up	Sep 75- Sep 76	FY 77	FY 78	FY 79 (6 months)
1. Publication Requirements	1,454.00	16,944.00	18,800.00	10,650.00	3,730.00
2. Training	12,812.00	8,100.00	8,460.00	208.00	260.00
3. Granting Access	-	16,682.00	16,400.00	19,920.00	10,510.00
4. Correcting Records	-	4,171.00	4,100.00	4,980.00	2,625.00
5. Security and Control	6,786.00	-	3,860.00	915.00	-
6. Accounting and Disclosures New Data Collection	-	62,561.00	61,500.00	74,700.00	39,405.00
7. procedures	-	-	-	-	-
8. All Other Costs	25,601.00	120,218.00	114,900.00	73,760.00	36,365.00
Total	46,653.00	228,676.00	228,020.00	185,133.00	92,895.00

Mr. PREYER. Mr. English.

**STATEMENT OF MICHAEL J. ENGLISH, OFFICE OF LEGAL
ADVISER, ST. ELIZABETHS HOSPITAL**

Mr. ENGLISH. Mr. Chairman, and members of the subcommittee, it is my pleasure to have the opportunity to speak to you regarding implementation of the Privacy Act at St. Elizabeths Hospital.

My name is Michael J. English. I am an attorney in the Office of the Legal Adviser at St. Elizabeths Hospital.

At the present time, there are approximately 2,000 inpatients, 3,500 outpatients and approximately 4,000 staff members at the hospital. In addition to thousands of administrative and personnel records, we maintain at the present time approximately 130,000 psychiatric medical records.

I have included in my presentation a brief statistical summary that is attached to the back of my statement which gives a general outlook as to the amount of activity that has occurred relevant to the Privacy Act.

I would like to summarize my statement as it relates specifically to Privacy Act activities in relationship to psychiatric patients. In the access area, when we first began determining how to implement the special access provisions of the Privacy Act, there was a split among the clinical staff as to whether or not access would in fact create a problem if psychiatric patients were able to get access.

As a policy matter, we set a liberal guideline for access and provided generally that direct access would be given to our patients except in certain very limited circumstances.

The circumstances where we thought that a patient might not have direct access and we would have to use the intermediary provisions of the act were in the area of actually physically dangerous patients, patients who would either destroy the record itself or maybe perhaps the staff that were giving access; where the access request was to a psychotherapeutic note that is not a part of the medical record; and the third category, and the only one where we have had any intermediary activity at all, is where patients are not at the hospital and don't want to come to the hospital.

We felt that to determine likelihood of adverse effect, it was perhaps more important to see and be able to get a handle on the condition of the patient rather than just review the content of the record.

We have experienced 244 accesses to records since September of 1975. Obviously, this is a very small number depending on how you evaluate the number of people who could have access. Our best estimate is that we are talking about 1 access per 600 over a 3-year period. The number of accesses reflect, in our estimation, a hesitance or an uninterest on the part of our particular class of patients to have direct contact with the context of their record.

We have made significant efforts to assure that patients know that they have the right to access. The act itself does not provide a vehicle to give notice of rights. It gives responsibility to provide notice of certain other activities regarding the maintenance of the records, but not as they relate to rights to access, amendment or knowledge to whom the records were disclosed.

We have included in our admission forms and in our admission interviews, information about the access right. We have also established these rights as part of the patient's rights poster that is posted in all wards of the hospital.

We still have a fairly low percentage of accesses. In our estimation, the primary reason for that is that we are dealing with a substantially disabled population. The population of the hospital is generally very acutely psychiatrically ill or chronically ill and perhaps they do not have the wherewithal to exercise the rights that one might expect in the general population.

In the area of disclosure, I think our experience is representative of the experiences of most agencies, that the accounting provisions do pose a certain burden, that we have not experienced any requests for knowledge of to whom records were given.

So, the underlying purpose of the accounting procedure does not seem to be being fulfilled. We also find that the provisions in the Privacy Act relating to routine use do make the act nonhelpful in preserving confidentiality of records.

It is clear that a routine use can be written to allow for disclosures in many circumstances where confidentiality should be preserved. Our emphasis in the hospital has been to direct our training efforts at assuring that staff will get consent to disclosures in all possible situations, regardless of whether or not a routine use could be interpreted to allow for nonconsent disclosure.

We also have made great efforts to make sure that the staff continue to be aware of the physician-patient privilege that is codified in the District of Columbia Code and must be complied with when dealing with confidential records.

We feel that we have been successful in this effort and, that that is where we have been able to preserve in a much better way the actual confidentiality of records.

We have also had a great deal of experience in responding to requests for information from law enforcement agencies. We are in the District of Columbia. We have a number of patients who are brought to us from the White House by the Secret Service.

Generally, the provisions of the act which require a written request stating a legitimate law enforcement purpose have been effective in assuring that only legitimate disclosures are made to the various law enforcement agencies.

All law enforcement requests are cleared through our office. We have an opportunity to see them. We have had a very good experience in dealing with the law enforcement agencies and assuring that the information that they need to perform a legitimate law enforcement purpose is complied with, but that broad access to medical records is not occurring.

The agencies have generally been very cooperative and we have not had terrible difficulties except in certain circumstances where the individual agents themselves come in and ask for broad access to an entire record.

After discussions with them, we have been able to work those problems out. We generally limit our information to a law enforcement official to that objective or demographic data which they need to perform their functions.

We had anticipated the amendment section to be a significant area where we would have to do a lot of work. As a result, we set up what we called an Amendment Review Committee. We have only had seven requests for amendment of a medical record by patients of the hospital.

Even though our amendment procedure has not been tested to its fullest extent, we feel that the process that we have used to implement that provision of the act has been quite successful.

The Amendment Review Committee itself has taken an attitude that when a patient comes in and requests amendment—and, by the way, four of the seven were for complete expungement of the entire record—that there is a certain amount of effort that should be made to assure the patients that their rights are being looked after.

The individuals on that panel go to great lengths to assure that patients are at least aware that their concerns are being taken seriously. We had one particular instance where a patient wanted a note regarding an altercation deleted from the record because he was afraid that it would impact on his conditional release.

He was a criminally committed patient. We did a complete investigation. The process resulted in a determination that the note should be amended to the extent that there would be an indication that the patient was not the aggressor in the altercation.

We feel that the amendment section is very beneficial for the patients we have.

Finally, I would just like to say one thing and that is, implementation of the specific letter of the Privacy Act has been met. We have not had a great deal of difficulty in doing that. But, the success that we have had, I feel, is that we have been able to convince the staff at the hospital of the basic spirit of the act.

The use of the law to preserve confidentiality, to recognize the individual rights and the basic human dignity of each of our patients I think is the most beneficial aspect of our implementation of the Privacy Act. At St. Elizabeths Hospital, I think it's worked. Thank you.

Mr. PREYER. Thank you.

[Mr. English's prepared statement follows:]

PREPARED STATEMENT BY MICHAEL J. ENGLISH, ATTORNEY, OFFICE OF LEGAL
ADVISER, ST. ELIZABETHS HOSPITAL

Mr. Chairman, and members of the Subcommittee on Government Information and Individual Rights, it is my pleasure to have the opportunity to speak to you regarding implementation of the Privacy Act of 1974 at Saint Elizabeths Hospital. My name is Michael J. English, I am an attorney in the Office of the Legal Advisor at Saint Elizabeths Hospital. I, along with other members of the Hospital staff, have been responsible for development of policy and for implementation of the provisions of the Privacy Act since its effective date in September of 1975.

Saint Elizabeths Hospital is a federal mental hospital located in the District of Columbia which serves the citizens of the District of Columbia and certain federal beneficiaries. At the present time there are approximately 2,000 inpatients, 3,500 outpatients and approximately 4,000 staff members at the Hospital. In addition to thousands of administrative and personnel records, we maintain approximately 130,000 individual medical records of both the present and past patients. My purpose today is to speak to you regarding our experiences in implementing those provisions of the Act which specifically relate to medical records.

For your convenience, I am submitting with my prepared statement a brief statistical summary of the numbers of request for inspection of medical records, the numbers of requests for amendment or expungement of medical records and brief summaries of our responses to these requests. I would like to address my further comments to the substantive issues we have encountered in applying the Act.

Access

Prior to the effective date of the Act we held a series of discussions with clinical staff regarding the methodology we would adopt in implementing the modified access provisions of the Act applicable to medical records. At that time, there was a clear difference of opinion regarding the ramifications of patient access. One group of clinicians felt that access would be detrimental to the therapeutic process and could present a hazard while another group felt that access had potential benefits which outweighed the potential hazards. We adopted a liberal access procedure for the Hospital which is basically three-tiered. First, a patient requesting access can be given direct access with no intervention by Hospital staff. Second, if the staff believes that material in the record is likely to have an adverse effect, the patient is given direct access after the appropriate clinician has an opportunity to discuss the questionable portion of the record with the patient. Third, an intermediary is only used when (1) an access request is made by a patient who presents an imminent threat of danger to himself/herself, the staff or the record; (2) the request is for access to a personal psychotherapy note not contained in the medical record; or (3) the request is from a discharged patient who will not or can not come to the Hospital to obtain access.

A relatively small number of patients have requested access to their record (244) since the effective date of the Act. We have gone to great length to assure that patients are aware of their rights to access and are convinced that the majority of patients at the Hospital are either uninterested in obtaining access or are personally hesitant to exercise their right. In those cases where access has been given, we have experienced no deleterious effects. One clinician reports that after access her patient was disillusioned because the record reflected treatment failures and the chronicity of her illness. Other clinicians have reported that access to records has given individual patients a greater sense of participation in the treatment process and has been positively beneficial. We have had two instances where clinical staff have identified material in the record which they genuinely thought would be harmful to the patient and a third party. In both cases, information in the record identified relatives who had been informers to the police regarding a crime or had reported to the Hospital patient abuse of privileges. While the staff members were fearful that the patient might retaliate, in both instances direct access was given after the clinician had discussed the entry with the patient and no adverse effect result.

In preparation for this testimony, we polled the Privacy Act coordinators in each of the clinical divisions of the Hospital about their recent experiences with access. The uniform response was that requests for access had become

a routine event in the Divisions and compliance with the Act's provision for access has been easily carried out. In fact, some clinicians had developed procedures for giving unsolicited access to patients in order to avoid the paperwork connected with formal access under the Act, but after three years' experience even these clinicians have returned to the access procedure set out in the Act because the paperwork was not unduly burdensome.

Incompetent Patients

The Privacy Act makes no direct provision for personal representation of non-adjudicated incompetent patients. We have had some difficulty in assuring preservation of the rights guaranteed under the Privacy Act for adult non-adjudicated patients who in fact lack the capacity to make a judgment regarding either access or authorization for disclosure. In the area of access, we have avoided the problem because we allow patients access regardless of mental capacity and use the clinical staff to explain the entries in records to patients who have difficulty understanding them. Representation of incompetent, non-adjudicated adults becomes more difficult in the area of authorization for disclosure. We felt that the greatest potential for abuse existed in cases where patients would be asked to consent to disclosures when they could not understand the possible benefit or harm resulting from the disclosure. Therefore, we have required clinical staff who make disclosures to third parties to assess capacity and in those cases where the patient lacks the capacity to

understand, disclosure is being permitted where the staff identifies and documents that the disclosure will be for the benefit of the patient. However, we do feel that more adequate consideration of representation for adult, non-adjudicated incompetent patients in the Act itself would be preferable.

Notice of Rights

The Privacy Act does not require the Hospital to directly inform patients of their rights under the Act. It only requires that each person receive notice of the existence of records, the voluntariness of providing information, the purposes for which the record is maintained and the routine uses for disclosure of records without consent. We felt that our patients would be unlikely to exercise their rights under the Act if they had no direct notice and, therefore, have included statements of rights in the admissions forms and have listed the Privacy Act rights in the patient's rights posters that are posted throughout the Hospital.

Disclosure

In view of the wide range of circumstances in which disclosure of information is permissible without consent, we have concluded that the Privacy Act is not completely effective as a vehicle for maintaining confidentiality. However, by assuring that staff continue their awareness of the more strict confidentiality provisions of the physician/patient privilege set out in the District of Columbia Code, we have been able to maintain control over non-consented to disclosures of medical records subject to the privilege.

Specifically, we had much difficulty in identifying legitimate situations where non-consented disclosure should be published as a routine use under the Act. We were presented with so many examples of situations where disclosure would be legitimate that we had to write broad routine uses rather than very narrow ones. To offset the potential for abuse, we have concentrated our training efforts on encouraging clinicians to seek the consent of patients for almost all disclosures, even if they could, legally, be made without consent under a routine use. My office has received literally thousands of calls from clinicians in the Hospital regarding the propriety of disclosures and we are convinced that the present broad routine uses are not abused. Also, we are preparing now a new set of routine uses which will be more narrow and directed to very specific situations.

We have had a great deal of experience in responding to requests for information from law enforcement agencies. Generally, the provisions of the Act which require a written request stating a legitimate law enforcement purpose have been effective in assuring that only appropriate disclosures are made to the various law enforcement agencies. All law enforcement requests are cleared through our Office of Legal Advisor and we have, on many occasions, been able to restrict the amount of information given to law enforcement officials to that objective or demographic data which they really need. There is a propensity on the part of law enforcement officials to want broad access to all portions of the medical

record, but we feel that such access is neither in the best interest of the patient nor necessary for law enforcement functions. The discretion the Privacy Act vests in the Hospital staff to determine which constitutes a legitimate disclosure has been an effective vehicle for assuring the proper flow of information between the Hospital and these law enforcement agencies.

A major problem arises when we are required to respond to subpoenas. As you know, subpoenas are issued under the seal of the court, but are actually filled out and served by the parties to particular litigation. In many instances compliance with a subpoena places a particular patient in significant jeopardy, e.g., when records are subpoenaed in child neglect or custody proceedings. In response to this problem we have taken the position that a properly served subpoena does not eliminate our responsibility to assert other privileges as a defense against disclosure of the medical record in particular judicial proceedings. In several instances we have asked the court to appoint counsel for the patient specifically for the purpose of responding to the subpoenas and the procedure has been effective in certain instances. However, the volume of subpoenas for medical records is such that we have not yet finally identified a procedure which is fully responsive to the problems presented by subpoenas.

Amendment

Since implementation of the Act in September of 1975 we have only experienced seven requests for amendment of medical records. Interestingly, four of the seven requests were for complete expungement of an entire medical record. One additional request was for expungement, but later was changed to a request for clarification. In anticipation of requests for amendments of medical records, we established an Amendment Review Committee at the Hospital to which all requests for amendment are submitted except in the case of clear, simple factual errors which can be corrected by division personnel. Although our experience has been limited, use of the Amendment Review Committee has been positive. In each case where a amendment request was made by a patient, the Amendment Review Committee made special efforts to assure the patient that their request was being reviewed in detail and every effort was being made to give adequate consideration to their request. In a particular case, one of our criminally committed patients requested expungement of a note in the medical record relating to an altercation on the ward. While the Amendment Review Committee felt that complete expungement was inappropriate where the note had clinical significance, a full investigation was completed and the writer of the note was required to clarify the note to show that this particular patient had not been the aggressor in the altercation. This result satisfied the patient and also assured system fairness by preventing the possibility that the patient would not be conditionally

released from his criminal commitment because of his participation in the altercation.

Perhaps the most significant problem identified in regard to the amendment of medical records is the method by which changes would be made in notes expressing clinical judgment, diagnosis or prognosis. To date, we have not experienced the problem directly except in the cases of requests for expungement. We presently are of the opinion that factual errors in the record should be changed but that notes stating clinical opinion should not be physically removed from the record but instead modified by addition of corrections.

While I have limited my testimony to those aspects of the Privacy Act which directly relate to medical records, implementation of the Act at Saint Elizabeths Hospital has affected all other Hospital records. In fact, requests for access to employee records have been greater than those for access to medical records. Accounting for disclosures of records has been the most costly area of implementation. But, considering our experience of the past three years, we have concluded that implementation of the Privacy Act at Saint Elizabeths Hospital has been well accepted and beneficial for both patients and staff. Finally, I would like to emphasize that preservation of confidentiality and protection of the right to privacy is best achieved when people responsible for implementation are committed to preserving the principles of human dignity and personal autonomy underlying the spirit of the Act. The staff of Saint Elizabeths Hospital adheres to the spirit of the Act; compliance with its letter has not been difficult.

Saint Elizabeths Hospital Privacy Act
Implementation Statistics

	<u>9/25/75</u> to <u>12/31/76</u>	<u>1/1/77</u> to <u>12/31/77</u>	<u>1/1/78</u> to <u>12/31/78</u>	<u>1/1/79</u> to <u>3/31/79</u>
I. ACCESS: *				
Patients	143	44	35	22
Employees	608	365	455	75
II. AMENDMENT:				
Patients	3	2	2	0
Employees	0	2	1	0
III. RESULTS OF AMENDMENTS:				
Patients:	2 factual requests granted			
	5 expungement requests			
	a. 4 denied			
	b. 1 granted (through clarification of record)			
Employees:	2 factual requests granted			
	1 granted (through deletion)			
IV. COSTS:**	<u>9/25/75</u> to <u>12/31/76</u>	<u>1/1/77</u> to <u>12/31/77</u>	<u>1/1/78</u> to <u>12/31/78</u>	<u>1/1/79</u> to <u>3/31/79</u>
	\$27,649.57	19,229.10	25,492.76	12,023.38

*All requests for access granted.

**These figures are approximations. They do not reflect costs of xeroxing records since most SEH patients are indigent.

Mr. PREYER. I think you have all done an excellent job of putting your testimony in a nutshell. I certainly agree with Mr. English's last statement, that good laws will not work if they are not administered in the right spirit. Even bad laws will work if they are administered properly or in the right spirit.

I remember some years ago, James Landis was appointed head of the Special Committee To Study the Regulatory, Administrative Process in Washington. After spending a lot of time studying it, his conclusion was exactly that, that there was not much you could do about it except get good people to administer the law. That was about what it amounted to.

On the question of your use of intermediaries, HEW requirements require that individuals seeking to inspect their medical records must designate an individual to review the record in the event that access to the record might have an adverse effect.

I gather in the Indian Affairs, Mr. Johnson says, you appoint a representative in every case?

Dr. JOHNSON. That is correct.

Mr. PREYER. And so, the problem of designating beforehand or not designating does not arise.

Dr. Erickson, in your situation, do you designate a representative in advance for everyone seeking access to his records? How do you work that?

Dr. ERICKSON. We do not request the designation of a representative until usually after the patient has discussed his or her case with a PHS staff member since we found that most things can be resolved at that level, anyway.

However, if the patient is not satisfied, the records are released to a designated representative with our comments regarding any adverse effects, if one of our staff would ever feel that releasing that information directly to the patient might be difficult.

But, that has posed no problem for use since we try to have the best doctor-patient relationship, health profession-patient relationship and usually, that has worked with the record and the patient and the health professional.

Mr. PREYER. How about you, Mr. English? Do you designate a representative in advance?

Dr. ENGLISH. We require the designation of a representative in all cases where the patient is not at the hospital or who is unwilling to come to the hospital. In the cases where the patients are at the hospital or are willing to come into the hospital, we do basically the same thing the Indian Health Service does, which is to allow the clinical staff to discuss with the patients the records and then give direct access. That is how we handle the intermediary provisions of the regulations.

Mr. PREYER. I would like to ask all three of you how often have you found that records have been withheld because of adverse effects?

Mr. JOHNSON. We have no case.

Mr. PREYER. Not a single case.

Dr. ERICKSON. I am not aware of any.

Mr. ENGLISH. We have had none. We had two cases where the staff there might be adverse effect. But in both cases, direct access was given and no untoward events occurred.

Mr. PREYER. One final question on the access problem. The rule says the representative may be a health professional or "another responsible individual." Who decides if the designated persons is responsible? Has that been a problem for any of you?

Mr. ENGLISH. Where we are giving access to a patient who is not at the hospital, where we cannot see what the condition of the patient is, we have basically made the policy determination that a responsible individual in this situation would have to be a mental health professional.

And so, we have required intermediaries to be mental health professionals, either a psychiatric nurse, psychologist or psychiatrist.

Mr. PREYER. Not a family member?

Mr. ENGLISH. No.

Dr. ERICKSON. We have experienced no problem with this because it is a member of the PHS staff who has made a judgment as to the competence of the designated representative. We have experienced no problem with that.

We do not require necessarily that the person be a physician or a nurse, for example. It could be a clergy person, for example, or it could be a social worker or somebody else.

It does not necessarily have to be a health professional, however, either.

Mr. PREYER. A member of your staff makes that judgment whether the person is responsible?

Dr. ERICKSON. Yes.

Mr. JOHNSON. We have no special criteria at all. Anyone who is designated, we will accept. We have a health professional available to assist them under any circumstances.

Dr. ERICKSON. As would we.

Mr. PREYER. I think I have taken up my 5 minutes.

Mr. Kindness?

Mr. KINDNESS. Thank you, Mr. Chairman.

I apologize for being both tardy and distracted here.

Dr. Erickson, in your testimony, you indicated that your Bureau has serviced about 10,000-plus access requests since 1976. The Indian Health Services had about 2,200. Could you explain the difference in population of records there, or what is the basis for the difference in numbers so we have that clear on the record?

Dr. ERICKSON. Well, since we were not keeping statistics prior to that, Mr. Kindness, on how many people asked for their records, since it was not required before the act, I am not sure.

We simply felt that as our beneficiaries heard and knew about the act as time went on, that that was one reason why the increase.

Mr. KINDNESS. But, is there not a larger population, a larger number of records to begin with in your case?

Dr. ERICKSON. Yes. We had 6 million records right to begin with. Although, the number of inpatient admissions which we had would be lower than Dr. Johnson's for example, as well as the number of ambulatory care visits simply because he has more facilities than we do.

Mr. KINDNESS. So on a current basis, would it be fair to state that the requests for access are generated pretty much by current treatment rather than people going into past records?

Dr. ERICKSON. Yes. I would guess that would be correct.

Dr. JOHNSON. There might be another point here, Mr. Kindness. The records in the Indian Health Service are held in local community Indian hospitals and clinics. It is sort of the family doctor, local community hospital kind of a circumstance.

The records are always there. The patients know where they are and they can come back and forth. Dr. Erickson's clientele is much more transient. There would be cases where a patient who is transiently in New York and is going someplace in the country might feel a need to look at his records because he might not be coming back to New York for a while.

That might be a reason for the disparity.

Mr. KINDNESS. This is for all three of our witnesses, if you please. In providing patient access to their records, what sort of safeguards do you apply with respect to the information that may have been provided by a third party in confidence?

Mr. ENGLISH. We take the position that information that is going to be placed in the medical record is not provided in confidence and that anything that is in the record is going to be accessible.

We have only one exception to that and that is in our forensic investigatory materials where we are doing criminal mental examinations and we are receiving information from the U.S. attorney's office or the defense—not the defense counsel, but the FBI or the policy, which is not discoverable in the criminal proceeding.

But, besides that, we do not pledge confidentiality for records that would be placed in the medical records. In fact, we do not pledge confidentiality for any records that we have, except perhaps the confidentiality of the name of a reference in an employee reference situation.

Dr. ERICKSON. We have had no difficulty with this, Mr. Kindness, since what is in the record is in the record and that is what the Privacy Act covers and we have always handled that confidentially with the patient in the past.

It has posed to my knowledge no difficulty with us since we are talking about what is in the record. We do not ask people who have other entries in the record as does St. Elizabeths. It is just part of the record.

Dr. JOHNSON. We have the same practice.

Mr. KINDNESS. The accounting that is done—there has been some reference by Mr. English at least, as to a question as to the value of the benefit derived from that accounting. Would you, Dr. Erickson and Dr. Johnson, care to comment on that aspect of it?

Is the cost of the accounting pretty much justified or does it appear that maybe there is a point to be considered here a little more closely as to whether the accounting is really a necessary cost?

Dr. ERICKSON. Mr. Kindness, all I can answer to that is that we have no record of anyone asking to see the accounting for the medical record. During fiscal year 1976 and 1977, 26 percent of the cost was the percentage for that accounting.

In the recent record, it is my understanding, the GAO estimated that the accounting requirements represented about 26 percent of the accounting for all Privacy Act costs. That was true for 1976 and 1977. This has gone up to 40 percent, probably due to the high requests for access to records and the number of man-hours, therefore, required to provide access, in 1978.

We feel it is important that the patient have knowledge of who has had access to their record. However, in lieu of that, appropriate authorizations could be on file with the hospital. That is just reporting what our experience has been in terms of cost. So, we are running about what GAO predicted.

We have had no one asking to see the accounting for the medical records.

Mr. KINDNESS. Dr. Johnson?

Dr. JOHNSON. We have the same experience. No one, to my knowledge, has asked to see an accounting. I think much of the accounting is of little or no value. For example, much of the accounting has to do when you refer patient records to a consulting physician or a laboratory, or X-ray, things like this. It is obvious that they have been referred because you have notes, you have reports back in the file, in the chart from these kinds of activities.

We would see value, however, in the accounting being limited to disclosure to law enforcement or for subpoena. I think there is a legitimate place to have an accounting record made. But, for the routine use which is really based on continuity and followthrough on patient care, that serves no useful purpose and it does add to the cost and the workload of already overworked professionals in our facilities.

Dr. ERICKSON. I would agree with that.

Mr. KINDNESS. Is there any comment you would care to make about the cost of training your personnel to deal with the requirements of the law?

Dr. JOHNSON. I do not think that has been a problem. We take the position that what the law requires is really good medical record practice. It seems to me we need to be doing these things whether you have a law or not.

Mr. ENGLISH. Our training efforts have been fairly significant. I think that is reflected in the attitude that we have regarding the need to assure that people understand the fundamental principles associated with the act.

But, that is to me the most important expenditure and that it is worth the time to spend with your staff to make sure that they understand the spirit of the act because then, they can handle the bureaucratic aspects, the filing of forms and things like that.

I think that has been time and money well spent at Saint Elizabeths Hospital.

Mr. KINDNESS. Thank you, Mr. Chairman. I think maybe my time has expired.

Mr. PREYER. Mr. Drinan, do you wish to question now before we go to vote?

Mr. DRINAN. All right, Mr. Chairman.

I wonder if Mr. English would comment on the exemption granted in the law to the Secret Service. You mentioned that you had some dealings with the Secret Service.

In the testimony this morning, they are seeking total exemption under section 112(a), but they are not protesting the nonexemption of the law. Do you think the Secret Service should have this exemption so that they can get this information without the restrictions of the act?

Mr. ENGLISH. Mr. Drinan, I am not specifically prepared to comment on the substance of the proposed legislation. But, based on our experience, there are indeed specific instances where we feel that the Secret Service should have access to medical records.

I think that a complete open door does one thing, and that is, it does not allow for a reasonable approach to looking at records to see what part is really relevant to their activities and what parts are not.

As I said earlier, the main problem is where people want everything so that they can go through and pick out what they might want. We feel that in psychiatric records, with the stigma associated with the label of mental illness and the label of being a St. Elizabeths patient, that there must be some control.

And, as I said, the controls that are set out in the Privacy Act which I do not believe are tremendously interfering with the activities of the Secret Service as they relate to us now, are sufficient.

Mr. DRINAN. Therefore, you would say that they do not really need the particular exemption that they have asked for?

Mr. ENGLISH. As I said, I am not exactly sure of what the exemption is.

Mr. DRINAN. I will quote: "Some States have a more restrictive mental health code than others but, generally speaking, all State mental health codes cause the Secret Service problems to some degree."

And that, as a result, he does not want this bill to deny them the access that they claim they need. In Massachusetts, for example, they do not get access. As far as I know, the Secret Service cannot do what they do in other States.

Would you want to comment on that?

Mr. ENGLISH. We have had experiences with what we call White House cases, individuals who have gone to the White House claiming to be the President or God or somebody, claiming to be there to take over the White House, or they are going to kill the President or something like that.

They come to us. Obviously, there are very significant reasons why the Secret Service should have access to information about these patients from us. The only point that I would make is that how much, how much information is sufficient to allow for the performance of a very legitimate law enforcement activity and where do you draw the line in trying to preserve the sensitivity of the clinical notes, the kinds of very personal kinds of information which are in our records.

And I said that I personally do not think that there is a need to overly restrict access. I think we have had a very positive experience with the Secret Service as well as all other law enforcement agencies, but that a carte blanche approach does not allow for the reasonable and orderly consideration of what aspects of the records should be disclosed.

Mr. DRINAN. I gather you are saying as far as you feel, the Secret Service should have the same restrictions as the police and other law enforcement people and with the cooperation that you would give them, that they could exercise their protective function?

Mr. ENGLISH. Our experience indicates that that is true.

Mr. DRINAN. Thank you very much.

Mr. BUTLER. I have no questions, Mr. Chairman.

Mr. PREYER. Perhaps we should—

Mr. KOSTMAYER. I will have no questions of these witnesses, Mr. Chairman.

Mr. PREYER. I have a few more questions of you, if you do not mind. We will recess for about 10 minutes.

[Recess.]

Mr. PREYER. The committee will resume sitting.

I would like to ask all the members of the panel if the access provisions have resulted in the keeping of two sets of records.

Mr. English, I think, mentioned that some notations are not made available. Or, is there any evidence that less information about the patient is being made available in his file because of the fear of access; that is, are doctors being more careful about what details they put in the record about the patient's illness or about the treatment for fear of protecting themselves against the lawsuit or something like that later on?

I want to start with Mr. English on that.

Mr. ENGLISH. Mr. Chairman, I think I can answer your question anecdotally. This week, St. Elizabeths Hospital is being surveyed for accreditation. Part of that is a substantive and detailed review of the medical records kept by the hospital.

Any potential for problems associated with detailed records as it relates to the Privacy Act is a bit of minutia when compared to the problems that we would have if we did not have that detail in those records for accreditation.

I think the statement was made before that what we are talking about is good medical records practice. That is the case in our view.

The Privacy Act and the permissive access that the Privacy Act sets out in no way has limited the content of records at St. Elizabeths Hospital.

I would like to maybe clarify perhaps your understanding of my statement regarding separate records. We have acknowledged that some clinicians perhaps will keep their own records regarding individual psychotherapy and that that record, because it represents only the speculations of the clinician, might not be entered into the official medical record.

However, those are identified as part of the system of records under the Privacy Act and it is accessible. The only thing that we do is we have said in our policy that intermediary access might be more appropriate in those circumstances because of the very speculative nature of the record.

My personal feelings is that there are very few if any clinicians who actually maintain those records.

Mr. PREYER. So, they are not hidden records in any sense? A notation is made that the record exists?

Mr. ENGLISH. We went to great lengths to identify all records, not just official medical records. We have another file that contains

all the raw data of the psychological tests. If a patient wants access to his psychological raw test data, he can get it.

Dr. ERICKSON. We have not had any difficulty with this, Mr. Chairman. I am not aware that physicians are recording less than they would have before. We, like St. Elizabeths, have always maintained that it is important to keep the best medical record you can which you need to treat that patient.

I do not think there has been any difficulty from that perspective.

Dr. JOHNSON. I do not think any necessary or substantive information is being withheld from the record. I think that it has forced physicians and other providers who make notes in the record to be very careful as to how they present facts.

I think some casual comments that might have slipped into records in the past are no longer slipping into them. But, I would look upon that as a very beneficial effect of the act. They should not have been there in the first place.

Mr. PREYER. Mr. Weiss? I apologize to you.

Mr. WEISS. Thank you, Mr. Chairman.

I have no questions.

Mr. PREYER. Are there any further questions of these witnesses? We do have a number of other witnesses today. We appreciate their testimony being put as concisely as you put it and it is very excellent testimony.

Mr. DRINAN. I would like to expand on a point that I brought up before, that under the bill before us not only does the Secret Service have some exemption, but also the counterintelligence agencies which would be the FBI in part and the CIA.

I wondered, Mr. Chairman, if any of the witnesses would want to comment on their experiences with the FBI or with some counterintelligence agency in this area.

Mr. ENGLISH. We have not had any experience with the CIA involving counterintelligence. I do not think our patients are the subject of those kinds of investigations. If we have had some experience with the FBI in the performance of their investigatory functions as they are seeking out enforcement of Federal laws, we have handled those encounters the same way we have handled the encounters with the Secret Service and the Metropolitan Police Department of the District of Columbia.

And I think, generally speaking, my recollection is that we have had about the same experience. We have not been involved in any more difficult problems, but we have still had to look at requests to assure that the access is not overly broad.

But, no real problems. We treat them the same way.

Dr. ERICKSON. Mr. Drinan, we also have had the same situation in our facilities. We do not deal with the FBI or the Secret Service, I would guess, as often as St. Elizabeths, but it does occur and it is done either with patient authorization or on subpoena.

Mr. DRINAN. The case of the Secret Service and the counterintelligence agencies would be that they cannot get a subpoena because no crime is committed. This is only for counterintelligence purposes.

Dr. ERICKSON. We have had no dealing with them, so it is difficult for me to comment on that.

Dr. JOHNSON. To the best of my knowledge, we have had no dealings with either counterintelligence or Secret Service.

Mr. DRINAN. Thank you very much, Mr. Chairman.

Mr. PREYER. Thank you very much. We appreciate your being here today. We hope you will allow us to keep in touch with you as questions occur to us from time to time.

Thank you for your testimony.

Our next witness today is returning for a second engagement. John Shattuck, director of the Washington office of the American Civil Liberties Union, was to have presented testimony to us on April 11. We ran out of time.

We appreciate your patience. Mr. Shattuck, your earlier statement has already been inserted in the record. So, it might be helpful if you can bring us up to speed briefly on what your earlier statement said and then, we will proceed with questions.

STATEMENT OF JOHN H. F. SHATTUCK, DIRECTOR OF THE WASHINGTON OFFICE OF THE AMERICAN CIVIL LIBERTIES UNION

Mr. SHATTUCK. Thank you very much, Mr. Chairman. Let me say at the outset that the ACLU applauds the leadership that this subcommittee has shown on privacy issues by conducting these hearings on the confidentiality of medical records and that we believe there is probably no more important area for privacy protections to be brought in by Congress than this very extensive area of medical records.

I have submitted for the record, Mr. Chairman, a supplement to my statement of April 11 which compares or begins to compare some of the legislation in the area. I will be submitting additional material for the record and I hope you will bear with me until it arrives, sometime within the next few days.

Mr. PREYER. Without objection, that will be made a part of the record. We will welcome any supplements and additional materials as you may wish to file them.

Mr. SHATTUCK. There are two major kinds of privacy problems that result from the handling of records that are generated by the billions of encounters that occur every year between doctors and patients. The first is that most patients are unable to get access to their own records to find out whether they are accurate and whether they would be damaging or how they would be used if they were to be disclosed.

The second, ironically, is that just about anyone else except the patient himself or herself is able to get access to medical records for a very broad variety of purposes.

What I would like to do at the beginning of my oral presentation here is to give you some examples of what this means in practical terms. In many cases, it means that instead of being helped by medical records, which is presumably what the purpose of medical records is, people are injured by them by the loose dissemination and the way in which they are used, often, in the marketplace.

Our case files at the ACLU are filled with graphic examples of the kind of harm that often results from the way in which medical information is loosely disseminated today. Let me just give you a few.

In 1974, a man reported to the New Jersey Civil Liberties Union that he had lost his job with the Newark Board of Education and had been denied two life insurance policies because a credit reporting company had obtained access to his medical records without his knowledge or consent and had reported to his employer and prospective insurers that he suffered from an emotional disorder because he had been treated as an outpatient at a mental health facility.

He had no knowledge that this medical information had been disclosed.

A second case involved a woman who reported to the ACLU in 1975 that despite her Phi Beta Kappa college degree and her score in the top 1 percent of the national medical college admission tests, she had been turned down by some 13 medical schools because medical records obtained by these schools had showed that she had once been a voluntary patient in a psychiatric institution.

In a third case, a New York man reported to the ACLU in 1976 that he had been denied a license to drive a taxi because a credit report showed that when he was 13 years old, he had been placed in a mental institution because he was an orphan and the mental hospital was the only home authorities could find for him for 6 months.

In a final example that I have cited in my earlier statement, a New York statute requiring physicians to report all prescriptions of certain medical drugs, including the names and addresses of patients using them, to a central computerized data bank in Albany was upheld in 1977 by the U.S. Supreme Court in a case handled by the ACLU.

I think this demonstrates the difficulty that one has under current law in making constitutional challenges to the broad dissemination of medical records.

To put these cases in perspective, I would like very briefly to describe the three most common types of medical records disclosure over which patients have little or no control.

First are the disclosures to private and Government insurers. As you have heard from many witnesses in these hearings, insurance companies generally obtain all kinds of medical information both from the insured person and from doctors and hospitals.

Theoretically, this is authorized by the patient. But, in practice, the authorizations that are signed are often so broad as to be virtually meaningless, and it is necessary to sign that authorization in order to obtain the insurance.

An insurance applicant simply signs on the dotted line and that provides for access to virtually all the medical information that is available about that person to the insurance company that is weighing the insurance application.

The second major consumer use of the medical data is for health evaluation planning and research. And here, we have publicly funded health services routinely monitored by Government agencies at the Federal, State, and local levels, all important to be sure, but with no privacy protections built into that process.

One of the most controversial and probably growing practices of monitoring of health delivery is the so-called Professional Stand-

ards Review Organization. This was established by the 1972 Social Security Act.

This organization consists of a network of medical professionals who review the treatment of medicaid and medicare patients and other types of publicly funded health care.

It is likely, I think, that these PSRO's as they are called, are going to be growing increasingly if we move toward broader national planning of health insurance. Here, there are no privacy protections built in at all.

As far as research is concerned, confidentiality is a continuing and growing problem as you have heard from other witnesses in the hearing. Sometimes it breaks down completely.

Let me give you an example from the ACLU's experience. In 1976, a study was conducted under the auspices of the National Institutes of Health in New York to learn the effects, the long-term effects of having an abortion on some 21,000 women.

The study apparently involved the matching of fetal death certificates with other personal, marital, and medical records of women all over the country. None of the women whose records were studied had given their consent or even knew about the study.

But, when a report on the study was submitted to the New York State Legislature, a number of names of subjects were disclosed. They were thereby stigmatized by the fact that they had actually had abortions.

Now, this was not—there were no privacy protections built into that study, certainly no protections similar to those being considered by the subcommittee.

The third major type of medical record disclosure is for purposes totally unrelated to medical care or evaluation or research and that is in the area of law enforcement.

The police generally claim, in our experience, that medical records are an important investigative tool. But, there is very little evidence to show that medical records, unlike, say, financial information, are as generally useful for law enforcement purposes as are claimed.

But whatever the utility of medical records may be for law enforcement, the point is that the police seem to have little difficulty in obtaining access to medical data. Police are sometimes—we are told by our affiliates in the American Civil Liberties Union—permanently stationed in large metropolitan hospitals so they can have easy access to the medical records room.

That seems to be the practice in many places.

In any event, I think as you have established in these hearings, the erosion of medical privacy in this country has been enormous and is certainly growing.

In our view, there are four major principles which must be incorporated into any legislation which is going to stop this erosion and which would be worth enacting.

These are, first, a right of access by patients to their own records and a right to correct demonstrable inaccuracies in the record. This includes the right of realistic informed consent to each dissemination of the records.

Second, there must be a clear and statutorily defined expectation of confidentiality with respect to all medical records wherever they

are, whether they are in the hands of hospitals or if they have been disseminated and they are in the hands of researchers or some other third party.

The third principle is that every authorized use of medical records outside of the doctor-patient relationship should be very clearly justified on the public record in these hearings so that there is no authorized use that slips into a bill that is supposed to be protecting medical confidentiality and is not subject to the kind of scrutiny that this subcommittee should be giving it.

And fourth, all other nonmedical uses of medical records should be prohibited unless they are specifically authorized by the patient or required in specific cases by judicial process.

Now, let me move quickly to the two major pieces of legislation that are before you, the two bills. These principles that I have spelled out are reflected to some extent in H.R. 2979 which has been introduced by Chairman Preyer and to a far lesser extent—and, in fact in many cases, not at all—in the administration's proposed Medical Privacy Act, H.R. 3444.

I would like to tell you which issues the ACLU regards as most important in these two bills and indicate why we believe that H.R. 2979 is a much better vehicle for legislation than the administration's bill.

The first major issue is the patient's control over the use of information. In this area—that is the right of access, the right to correct inaccurate information, the right to limit disclosures to those by informed consent—the two bills are roughly similar and the administration's bill is not—does not fall behind the principles I have outlined.

But, in the second major area, disclosure without authorization by patients, the provisions of H.R. 2979 are much superior. The administration's bill presents a very long catalog of permissible disclosures, many of which were not recommended by the Privacy Protection Study Commission, which is the underlying document for all of this regulation, and which do not have the kind of empirical justification which I think is needed in order to come into this disclosure without patient authorization area.

There is one major flaw in H.R. 2979 in this second category of disclosure without patient authorization, and that is the very broad Secret Service and foreign intelligence authorization which Father Drinan was questioning the previous witnesses about, section 120, which makes sensitive medical records available to the Government merely on a "written certification signed by a supervisory official of a rank designated by the head of the Government authority that the record is being sought for a legitimate Secret Service or foreign intelligence purpose."

I am quoting from section 128 there. This provision appears in both of the bills before you and is wholly at odds with the efforts here to protect the confidentiality of medical information, and also the effort that is going on in the House Intelligence Committee and in the House Judiciary Committee to bring to bear statutory controls and restrictions and charters for Federal intelligence agencies.

I think if the kind of broad access that were allowed the Secret Service and the CIA and other foreign intelligence agencies under

this provision were enacted into law, it would mark a major departure from the not wholly acceptable, but nonetheless clear procedures that are established in the last year's Foreign Intelligence Surveillance Act, the Wiretap Act that passed the Congress, which provides for judicial authorization of foreign intelligence surveillance, wiretaps, any kind of electronic surveillance involving counterintelligence, including, of course, any wiretaps that might be conducted by Secret Service.

We are very strongly opposed to that provision and urge the subcommittee to look closely at it, and, of course, to question the Treasury Department witnesses closely to find out precisely why the total exemption for the Secret Service is provided in here.

Let me just say that you need only think of the kind of access that the Government obtained to the records of Daniel Ellsberg's psychiatrist which was widely regarded as inappropriate and abusive. And, under the provisions of this bill, if a claim could be made by the CIA or by anyone else that it was necessary to get access to those records of Ellsberg's psychiatrist, it would be appropriate. It would be authorized.

One of the major issues in the Watergate period would result in going quite the other way, I think, if that provision were to be enacted.

The third major issue is the procedure for Government access outside of the foreign intelligence and surveillance area, that is, general Government access to medical records.

Here, the administration bill simply imports verbatim the standards of last year's Financial Privacy Act which are really quite low with respect to Government access. It is relatively easy to obtain information about financial records under last year's Financial Privacy Act and I think it would generally be agreed, and certainly, the Privacy Commission pointed out, that medical information and financial information are very different and should be protected quite differently.

So fortunately, H.R. 2979, in this area, tries to establish a new standard, a higher standard to give additional protection to medical records with respect to efforts by the Government to obtain access.

One of the ways in which H.R. 2979 is an improvement in this area is that it eliminates the so-called formal written request procedures of the Financial Privacy Act which gives every Government agency the right to make a formal written request.

At the lowest level, the agent in the field would be simply able to go in and request financial information. This is not permitted in the medical area under H.R. 2979, but it would be under the administration's bill and we oppose that.

Another important feature of H.R. 2979 in this area is that it requires a balancing of the privacy interests of subjects' medical records versus the Government interest, the law enforcement interest in obtaining access to the information whereas the administration's bill does not weigh the privacy interest at all.

It would be necessary for a court to determine under H.R. 2979, that the Government's law enforcement need was so great that it could overcome the privacy, the presumed privacy interest of the subject of the medical record.

This is not the case in the administration's bill. There are a variety of ways in which the access procedures in Mr. Preyer's bill, H.R. 2979, could be improved.

For example, the provision for suspension of notice to patients whose records are sought for law enforcement purposes should be narrower in our view. It should be much more consistent with the recommendations of the Privacy Commission which limited the suspension of notice to circumstances where there was a likelihood that the materials would be destroyed or that the person would flee.

Normally, those are the circumstances where you go for a search warrant. That really is the appropriate way to proceed.

We also believe that the burden of proof in a proceeding to enforce a judicial subpoena or an administrative summons should be squarely on the Government.

There should be no requirement on the part of someone whose records are sought to come in and show why the law enforcement interest is not appropriate. Obviously, that is almost impossible to do and it might even involved a fifth amendment problem if you had to come in and explain why you think the law enforcement interest in your medical records is inappropriate.

You might have to come forward with information that should not be disclosed without waiving your fifth amendment right.

So, to the extent that H.R. 2979 requires some showing by the patient, we suggest that the Government should have the burden of proof in demonstrating the law enforcement interest.

Now, in recommending these improvements, we want to stress that Congress has already once established a very high standard of protection for medical records which it should be careful not to undermine, and it's often forgotten that this is the case.

Under the Freedom of Information Act, medical records in Government files are virtually exempt from disclosure, disclosure to outside parties from Government files.

You will recall the exemption 6 of the FOIA protects personnel and medical files and similar files, the disclosure of which would result in a clearly unwarranted invasion of personal privacy.

The courts that have construed that exemption have construed it to mean that personnel and medical files are per se exempt under the Freedom of Information Act and only similar files, files that are like the medical files, but are not medical, have to be shown to involve a clearly unwarranted invasion of privacy before they would not be disclosed.

So, I think Congress is enacting exemption 6 recognized how important and how different medical information is from other kinds of sensitive information. And it is important in considering this legislation that that protection should not be undermined.

I want to conclude with just one comment about another section of both bills and that is the provision relating to search warrants. In our view, Government access to medical information should be generally and almost exclusively through summons or subpoena rather than search warrant.

In the case of a search warrant, there is no notice obviously, no opportunity to contest any effort by the Government to obtain the medical information.

Now, it may be that if the target of the search warrant is himself or herself a criminal suspect and there is probable cause, the warrant should be issued if there is no other way to obtain the material.

But I think it is important to note that the bills as they are now drafted do not limit search warrants to that kind of situation. They appear to allow search warrants to be used when there is probable cause to believe that the information to be obtained would be useful in a criminal proceeding.

That does not mean the target that is to be the subject of a warrant. And in this respect, I think that the provision is at odds with what Congress is trying to do right now with respect to very broad authorization in the recent Supreme Court decision, *Zurcher v. Stanford Daily News*, which permits the Government to use search warrants to obtain access to records of innocent third parties, doctors, lawyers' offices, and newsrooms in the context of that decision.

So, we would recommend that the search warrant section of the bills be strictly limited to circumstances where the subject of the search is himself or herself a criminal suspect. I think that would be consistent with what is being considered and in fact, what has been recommended by the administration with respect to newsrooms in the effort to overturn the *Zurcher v. Stanford Daily* decision.

Well, I think that concludes my oral statement which is a composite of the statement that I presented before to the subcommittee for the record and some of the additional recommendations that we are making.

I would be happy to answer any questions that you have. Thank you, Mr. Chairman.

MR. PREYER. Thank you very much, Mr. Shattuck, for some very helpful testimony.

On the question of access, our bill, H.R. 2979, given a qualified right of access to medical records. Do you agree that that is proper, or do you advocate unrestricted right of access?

MR. SHATTUCK. Our position on the question of patient access is that the principle of access is based on the right to control information about yourself and to the extent that information is going to be disseminated and used to make judgments about you, whether it is medical information or something else, you should have an absolute right of access to it.

But, to the extent that it is going to be kept absolutely confidential, I think that we would recognize an exception to that absolute right of patient access. So that if, for example, the notes of a psychiatrist were to be subject to an absolute bar in terms of dissemination under this legislation, I think it would be reasonable or at least arguable that they could be kept from a patient if it could be demonstrated, as the bills now provide, that the patient would be severely damaged by the disclosure of that information to the patient himself.

But, to the extent that information is going to be used, is going to be disseminated outside of the doctor-patient relationship, our position is that there should be no exceptions.

Mr. PREYER. In the case you cited of psychiatric notes in which damage to the patient could be demonstrated, the question arises should he designate someone to represent the patient in that case.

Do you have any thoughts on who should be designated or what sort of restriction should be placed on that?

Mr. SHATTUCK. Well again, following the principle that the patient should be in charge, our position is that the patient should have a right to choose the most appropriate person. It may be that the subcommittee will determine to limit those categories of people to close relatives and doctors. I do not think we would be opposed to that kind of limitation.

But our position is generally that the patient should be able to control the way in which information is going to be used. And, if it is going outside of the doctor-patient relationship, then the patient should be able to say who the person is going to be.

But again, I think the subcommittee may want to determine that the appropriate limitation be that it is the patient's family and/or a doctor to whom it be disclosed.

Mr. PREYER. I understand the psychiatrists have taken the position or many of them have, that they should be entitled to keep notes apart from the medical record without any access to anyone, including any special representative.

One, do you think that is a good idea? I gather you do not. But two, what is to keep them from doing that anyway?

Mr. SHATTUCK. Well, I am not sure that we would object, Mr. Chairman, to those kind of notes being maintained and not disclosed to the patient if they fit the category of—I think the term in the bills would be “sufficiently harmful to outweigh the patient's privacy interest.”

But, the main point for us is that those notes must never get outside the doctor-patient relationship. There must be a prohibition in the legislation which would insure that no dissemination or use of materials that are not disclosed to the patient be authorized, including research purposes and audit purposes, and any of the other generalized exceptions to patient authorization that are contained in the bill.

Mr. PREYER. Incidentally, on the research auditing point, you cited a New York abortion example where names were used. Our research people would contend that in something like the swine flu situation where you have to have access immediately to a lot of records, that it cannot be done without using names or identifying files.

Do you have any problem with that use of files for research purposes?

Mr. SHATTUCK. To the extent that you can conduct research without names, you are obviously protecting privacy much more. If names and identities are needed, then again, the principle of no further disclosure without patient authorization or at least, without authority by the mechanism that is set up by your bill, which is in the case of research, I think, a professional evaluation unit which would determine that another use, research use, is so important that names would be used, but that the information will not be disclosed beyond that research purpose, I think we would find it acceptable that names be used, but, bearing in mind always that

the identities of patients and the linkup between the identity and the information about them, that is so damaging when the information gets out into the words, as I was pointing out in my examples, insurance companies, credit companies, all of the judgments that are made about people by prospective employers and by schools.

When that information gets out there, there is very little way to recapture it without the patient or the individual being severely damaged.

Mr. PREYER. It is hard to get that bullet back once it has been fired.

Mr. Kindness?

Mr. KINDNESS. Thank you, Mr. Chairman.

Thank you, Mr. Shattuck, for your statement. I think it is very helpful. Do you know whether there has been any work done by way of assembling examples of or information generally about the misuse of records by various organizations or types of uses such as you have cataloged in your statement?

I realize that there may be some informal gathering of information here and there. But, do you know of any assemblage of that information?

Mr. SHATTUCK. The best work I am aware of in this area is—has been by the Commission on Confidentiality of Medical Records and I believe they have testified before you already. They have, within the last several years, begun to systematically compile examples of the kind of information that I was giving you from our files.

Another place where this information is collected or has been collected is by Prof. Alan Westin who is perhaps the grandfather of privacy interests academically in this country and has written a number of very important books on the subject, including, most recently, a study of medical records and their uses and misuses.

I think that one could turn to him.

On the other hand, there has not been enough of the kind of pulling together of this information that I think the subcommittee is doing right now. Presumably, the record of your hearings will be very useful for that purpose.

But, I would be glad to supply you for the record with citations to some of the materials that I just mentioned to you and others as well.

Mr. KINDNESS. I would appreciate that. I suspect that in order to be very factual about it, you almost get into the situation where names need to be disclosed and the type of information that we do not want disclosed has to be studied.

But, I think somehow or another, we can fall somewhat short of that without any disclosures, at least to get a picture of what sort of misuse pattern may be apparent.

I would ask one other area of questions. In the case of any State laws that restrict the use of medical records information, do you have any information as to State laws that ought to remain in place and not be preempted by Federal legislation?

Are there examples that exist at the present time where we ought not to get in the way of the existing State laws?

Mr. SHATTUCK. I think that is a very good point. There is an evolving State law in this area, both decisional law and statute.

The State of Oregon, I know, has very strong medical records protection bill or act now which is perhaps slightly stronger than the legislation that you are considering.

In the area of decisional law, the California Supreme Court has had a number of important decisions in the area of financial data and financial records which I think implicate directly the privacy interest in medical records.

The Privacy Commission, the President's Privacy Protection Study Commission, did a compilation of State laws as of mid-1977 in the medical records area and I think that one of the important tasks of the subcommittee should be to make sure that no law that is stronger than anything that may come out of this subcommittee is overruled or preempted.

I believe the bill makes an attempt to do that now. Mr. Preyer's bill may need some clarification, but I think the attempt is there in one of the sections of the bill.

Mr. KINDNESS. Thank you, Mr. Chairman.

Mr. PREYER. Mr. Drinan?

Mr. DRINAN. Thank you, Mr. Chairman.

Thank you, Mr. Shattuck. I think it should be noted for the record here, as it was on April 11, that John Shattuck is the author of a textbook called "The Rights of Privacy," a volume which I found very helpful.

I really have no questions, Mr. Shattuck. Would you like to give me a question that you would like to be asked? [Laughter.]

Mr. SHATTUCK. You can ask me why the Secret Service and the CIA need the kind of protection they seem to be asking for.

Mr. DRINAN. That is a very good question. Why don't you respond?

Mr. SHATTUCK. I will respond by asking you to be sure to ask them that question when they appear before you.

Mr. DRINAN. The Oregon law permits disclosures if there is a clear and immediate danger to others. Do you feel that that could be too restrictive or is that acceptable?

Mr. SHATTUCK. A clear and immediate danger to others is the standard used to prohibit disclosures?

Mr. DRINAN. Permit disclosures.

Mr. SHATTUCK. That sounds like a stronger standard than we are talking about in the context of H.R. 2979.

Mr. DRINAN. It is. I wonder whether the ACLU would recommend that particular standard.

Mr. SHATTUCK. I think we would. We would certainly recommend anything that tilts in the direction of the kind of privacy provisions that we were talking about.

Mr. DRINAN. I wonder if you have any thoughts on the California Supreme Court decision that said a psychiatrist may be liable for failing to warn a third party that a patient poses a threat of serious danger.

That is possibly beyond the scope of this Federal law, but I suppose that we should take into cognizance the fact that California, and conceivably other States, do require a psychiatrist to disclose that a patient poses a threat of serious danger.

Mr. SHATTUCK. I would not want to respond quickly to that because I find that on its face a potentially dangerous authorization for psychiatrists to make disclosures to third parties.

Certainly, psychiatrists are going to have to take into account information that they learn that is of overwhelming importance to the safety of other people. But, to authorize them in this legislation to make those kinds of disclosures, I think, would be dangerous.

I assume that—

Mr. DRINAN. I do not think that we would authorize them, but we might possibly be asked to take into cognizance the fact that some States do require psychiatrists to do that. That is a very difficult question.

I thank you for your testimony on both occasions. I yield back the balance of my time.

Mr. PREYER. Mr. Evans?

Mr. EVANS. What would you say is the best organization that should approve the right of researchers to access to medical records?

Mr. SHATTUCK. Well, I think Mr. Preyer's bill makes a very good stab at that by requiring that there be a research evaluation unit outside of the researchers who are actually conducting the research.

The administration's bill permits the researchers to make certifications to the hospital that they are doing good research and then, the material gets disclosed.

I think a professional evaluation unit similar to the one suggested by H.R. 2979 would be appropriate. It is important that whenever there is a request for access to identifiable patient information, that that unit get involved.

I think for a researcher to make a further disclosure to another researcher is the kind of abuse or potential abuse that this legislation ought to be prohibiting.

Again, the administration's bill appears to permit that kind of lateral dissemination from one researcher to another. There must be a professional evaluation unit.

Mr. EVANS. You believe that Congressman Preyer's bill would be a step in the right direction?

Mr. SHATTUCK. I think that is right.

Mr. EVANS. And provide the correct organizational structure to make such a decision?

Mr. SHATTUCK. Yes. I think that was the general approach of the Privacy Commission as well. I know that Mr. Preyer has tried wherever possible to follow the recommendations of the Commission. For that, he is certainly to be commended.

Mr. EVANS. Thank you, Mr. Chairman.

Mr. PREYER. Thank you.

Mr. Weiss?

Mr. WEISS. Thank you, Mr. Chairman.

Again, getting back to the question of psychiatrists' notes and records, we had testimony earlier from a representative of the American Psychiatric Association, about legislation in Illinois which in essence treats a psychiatrist's notes and records differently than other physician's records.

Would you support a separate and different kind of treatment for the two types of records?

Mr. SHATTUCK. Getting back to the principle that I outlined in response to Mr. Preyer's question on that point, we would support that if there was an absolute prohibition against the disclosure of information contained in those notes and if it could be demonstrated that the information would be sufficiently harmful to outweigh the patient's privacy interest, again referring to the standard of the bill.

But, only if those two conditions are satisfied. Because, to use psychiatric information outside of the doctor-patient relationship would be very dangerous, probably the most dangerous of all possible authorizations.

Two of the examples that I gave you in the beginning of my testimony constituted just that kind of abuse. So, I think if the subcommittee goes down that road, it is very important to make sure that psychiatric records that are not disclosed to the patient are never permitted to be disclosed to anybody else.

Mr. WEISS. In H.R. 2979, there is a provision which provides that in the event records are made available to the Secret Service or other intelligence authorities, the medical care facility or employee of the facility shall disclose to any person that a Government authority has sought or obtained access to a medical record.

Now, that could mean that in fact, it cannot be disclosed to any other person than the patient. If that is what it intends, I think that is a salutary prohibition because it is bad enough having some governmental people looking at it, and then having the world know that in fact the Government is looking at those words.

I wonder what you would think of an amendment to this section which would make it very clear that the restriction applies only to persons other than the patient; that the patient in fact would have the right to know that the Government is looking at his or her records?

Mr. SHATTUCK. I do not think that would go to the heart of the problem, though, which is the kind of authorization that the Secret Service and counterintelligence are seeking to obtain.

Mr. WEISS. Assuming that we tighten those provisions up.

Mr. SHATTUCK. Under those circumstances, it would make sense to bar any third party from knowing that the information was disclosed. Further, I would recommend that you prohibit any use of the information obtained by the Secret Service or counterintelligence agency for any other purpose than the one for which it was sought and that it not be disseminated by them to any other agency so that be a self-contained authorization.

But, I would urge that the subcommittee, perhaps more strongly than with respect to any other single issue in this bill, not to grant blanket authorization for access without external checks for those kinds of intelligence purposes.

Mr. DRINAN. Would the gentleman yield?

Mr. WEISS. Certainly.

Mr. DRINAN. Is it the position of your organization, Mr. Shattuck, that section 128 should be dropped, excised from the bill? The whole thing?

Mr. SHATTUCK. No. I think our position would be that it should be brought into—well, it should either be dropped or it should be brought into conformity with the standards in last year's Foreign Intelligence Surveillance Act.

If it is dropped entirely, I think that it is then arguable that the authority to obtain that information still exists outside of the context of this bill. I am not sure that dropping the authorization would solve the problem unless there were a prohibition in there that made it clear that no medical information could be obtained by the Secret Service or foreign intelligence.

Mr. DRINAN. What specific aspects of that foreign intelligence bill would apply in this situation?

Mr. SHATTUCK. Well, we recommend that a judicial warrant procedure based on probable cause in regard to the foreign intelligence area, probable cause if the person is an agent of a foreign power as defined by that bill.

Mr. DRINAN. But, in the Secret Service?

Mr. SHATTUCK. Secret Service, I do not think we are prepared to make a recommendation until you have heard from the Secret Service exactly what kind of information they need and why. Absent that kind of recommendation, I think it ought to be probable cause that the person is engaged in a crime.

Mr. WEISS. I have only one other question in the health research area. There is at this point a great deal of activity and even greater interest in trying to identify individuals who were subjected to radiation hazards, for example, not only individually, but also by the military and other governmental people.

How would the recommendations that you have made and the testimony you have given affect the capacity of both the individuals who may not know about the fact that they were subjected to radiation hazards and to those organizations in and out of Government who are anxious to determine who those people were, both for compensation purposes and for health research purposes?

Mr. SHATTUCK. I think it would be possible to build that kind of access to individually identifiable data into the scheme of this bill and in fact, it may—H.R. 2979 may already permit that kind of access.

Presumably, for example, if OSHA wanted to obtain access to medical information of people working in a particular nuclear powerplant in order to determine what their medical histories were and what the likelihood that they are going to be suffering in the future from radiation, I think they would be able to obtain the kind of research access and closed unit evaluation that the bill provides, assuming no further dissemination of the information and general notice we would recommend, to the people in that nuclear powerplant.

It would be possible to have noticing from OSHA to all the employees of the Three Mile Island plant that they are going to have their medical records scrutinized for the purpose of determining radiation.

Mr. WEISS. How about the military people, for example, who were exposed to atomic bomb blasts because it was felt—well, for whatever reasons? How could you, within the strictures of this

legislation and your testimony, allow those records to be forthcoming?

Mr. SHATTUCK. Again, the research sections do provide for that kind of access. We do not oppose that, making sure there is no further dissemination. If a Government unit is going to be conducting research on military personnel long after events in question, like the Idaho testing or the Nevada testing, whatever, it would be possible for that Government unit to apply under the strictures of the research provisions of the bill to obtain access to that information.

It would not be necessary to notify the individuals, at the—obviously, you would not be able to notify them in the beginning because you would not know who they were.

The key point for us is always no further dissemination. No further dissemination of the data outside of the research context until the patient has been identified and told about it and is in a position to authorize further dissemination.

So that if the research is successful and it turns up the people and is able to say that they are likely to be subject to radiation, then it would be possible to notify them and any further use of their medical records would be within their control.

Mr. WEISS. Thank you.

Thank you, Mr. Chairman.

Mr. PREYER. Thank you.

Mr. Butler?

Mr. BUTLER. I have no questions, Mr. Chairman.

Mr. PREYER. Are there any further questions? Mr. Kostmayer?

Mr. KOSTMAYER. Just briefly. How do you fashion an exemption for these national law enforcement agencies and security agencies to enable them to do what they have to do without exceeding the standards which you have set?

Mr. SHATTUCK. As I said, I think it is possible to bring the counterintelligence agencies within the framework of this very carefully thought-out Foreign Intelligence Surveillance Act of last year.

Presumably, if the agencies are willing to submit to the limitations of that statute or are now forced to submit to them with respect to electronic surveillance, there should be no reasons that those same restrictions should not apply in the area of access to medical records.

Perhaps there is even stronger reason to apply this in medical records because the information obtained is at least as sensitive as that to be obtained by wiretapping. In the case of the Secret Service, I am not at this stage in a position to say what the standard should be because I do not know what the Secret Service would say about its need for access.

It it says that it needs to have general access to medical information about anybody in a city to which the President is going to be traveling or anybody else within the protection of the Secret Service, that just seems extraordinarily broad.

That is what this bill would authorize. It would authorize a Secret Service agent to go into a hospital in Louisville, Ky., and say we want to look at all your psychiatric records because the President is coming here. That is a discretion which knows no limits.

I do not think we can recommend limits other than the standard probable cause law enforcement limits until we have heard from the Secret Service.

Mr. KOSTMAYER. Thank you, Mr. Chairman.

Mr. PREYER. Are there any further questions?

[No response.]

Mr. PREYER. Thank you very much, Mr. Shattuck.

[Supplement to statement and additional material supplied by Mr. Shattuck follow:]

SUPPLEMENT TO STATEMENT OF JOHN H. F. SHATTUCK, DIRECTOR OF THE
WASHINGTON OFFICE OF THE AMERICAN CIVIL LIBERTIES UNION

Introduction

Americans average over five visits per year to physicians for medical advice and treatment. Each of these contacts typically generates either a new medical record or additional entries in existing records. The recommended minimum retention period for such information is between ten and twenty-five years. The tremendous growth in the amount of highly personal medical information in the hands of care providers - along with growing demands routinely satisfied for access to such information by third parties not involved in medical service delivery - has resulted in a serious erosion of the confidentiality of the medical care relationship. Today the decision as to whether or not to disclose medical record information to a third party lies within the discretion of the medical care provider. This discretion has been left unfettered by the courts which have for the most part upheld the autonomy of the medical care facility to control the dissemination of medical record information.

The parameters of the problem and the pressing need to find a solution stem both from the nature of the information collected in the context of the doctor-patient relationship and the variety of non-medical uses to which it is all-too-often put. Medical records typically contain much more than a straightforward documentation of the medical illnesses of a patient and the treatments administered to him or her. Records often include information regarding the patient's personal habits, social relationships, and attitudes and preferences as

perceived by the physician. As noted by the Executive Director of the American Medical Record Association, "a complete medical record may contain more intimate details about an individual than could be found in any single document." A partial list of those who frequently seek access to this personal information would include insurance companies, government service payers, welfare agencies, researchers, employers, licensing agencies, public health and law enforcement agencies, and credit reporting agencies.

While the need for information by such third parties may often be legitimate, a tremendous potential for unnecessary and unfair intrusions on the privacy of a record-subject is inherent in a system which places no real limits on the ability of a record keeper to disclose such highly personal information. The dangers of indiscriminate disclosure of irrelevant and at times inaccurate information is compounded by present practices which typically deny an individual an opportunity to inspect his or her medical records and to correct mistakes contained therein.

These problems are addressed in a recent report issued by the Privacy Protection Study Commission. A set of comprehensive recommendations have been developed by the Commission which if adopted should accomplish three related objectives. They are designed to (a) minimize intrusiveness (b) maximize fairness and (c) create a legitimate, enforceable expectation of confidentiality.

The central elements of the Commission's recommendations are as follows:

- (a) Creation of a right of access to one's medical records and an opportunity to correct inaccuracies in the record;
- (b) Establishment of a general rule that any disclosures will be limited to those authorized by the record-subject, with only a few carefully defined exceptions justified by a compelling societal interest in disclosure;
- (c) Limitations on the content of disclosures and the uses to which the disclosed information is put which reflect the purpose for which the disclosure is made;
- (d) Requiring that requests by government agencies for medical record information be made only through recognized legal process; and
- (e) Providing a record subject with an opportunity to challenge government access on the basis of the relevance and importance of the requested information.

The recommendations represent an important step in the direction of creating an enforceable expectation of confidentiality in the doctor-patient relationship. The three bills presently before Congress (H.R. 3444, H.R. 2979 and S.503) adopt, in varying degrees, the recommendations of the Commission. As such, they reflect a recognition of the importance that an individual's privacy interest holds in our society as well as the need to protect that interest from the destructive tendencies of ever increasing collection and dissemination of personal information. While praiseworthy in this respect, the bills depart in substantial respects from recommendations offered by the Commission and in so doing dilute the positive

impact on the confidentiality of the medical care relationship that the bills are designed to have. This report considers each of the bills in some detail, taking note of the deviations between the proposed legislation and the recommendations of the Commission. Each bill has strengths and weaknesses. To be worth enacting, any final version must reflect the strengths and eliminate the weaknesses.

Some general comments in summary form regarding the various aspects of the medical record privacy issue follow.^{*/} They address those areas where departures from the Commission recommendations are made in one or more of the bills, at the expense of the individual's privacy interest.

SUMMARY

Patient Access

Medical care providers should be required to respond to either written or oral requests for access to medical records. Providers should be required to develop a sliding scale so that charges of copying one's record are never so high as to discourage exercise of the right. Any standard to be used by a care facility in determining whether to deny direct access and to require disclosure of sensitive information to a third party designated by the individual, should not be so vague as to leave a service provider broad discretion.

Correction of Medical Records

Medical facilities should be required to make a prompt response to a request to correct a medical record. Thirty days would provide an adequate amount of time to do so. Should the

^{*/} A full and detailed comparison of H.R. 2979, H.R. 3444, S.509 and the Privacy Commission recommendations will be provided shortly to the subcommittee for inclusion in the record.

correction be denied, the health care facility should at the request of the record subject, be required to submit to prior recipients of the disputed information a copy of the requester's statement of disagreement, if one is filed. Similarly any corrections and amendments in the record should be submitted to prior recipients of the inaccurate record, if requested by the record subject.

Authorization for Disclosures

Any authorization of a disclosure should be in writing and should be specific as to the content and purpose of the disclosure. An authorization should contain an expiration date and should not be effective for more than one year.

Unauthorized Disclosures

In order to protect an individual's expectation of privacy, unauthorized disclosures should be severely limited. The Privacy Commission recommended a sharply limited number of circumstances under which unauthorized disclosures might be permitted. The Commission's recommendations strike a balance between the individual's right to personal privacy and society's needs for information about his medical condition. Each of the bills substantially expands the scope of permissible unauthorized disclosure. This expansion is dangerous and unacceptable. The provisions providing for unauthorized disclosure of information for law enforcement and foreign intelligence purposes as well as those relating to operation, evaluation and investigation of government funded programs, should be drawn far more narrowly. Many of the new categories do not seem to involve circumstances compelling enough to justify the erosion of an individual's

expectation of confidentiality that necessarily follows from a wide range of permitted unauthorized disclosure.

The Secretary should prescribe security standards with respect to the use and maintenance by researchers, auditors and evaluators of medical record information disclosed without authorization.

Government Access

In order to protect the individual's expectation of privacy, requests by government agencies for medical record information should be made only through recognized legal process. Provisions for access by formal request and exceptions to the legal process requirement - especially broad exceptions made for law enforcement, foreign intelligence and government program operation purposes - all undermine the protections afforded a record subject by other provisions in the bills. Only under the most compelling circumstances, if at all, should an individual be deprived of an opportunity to challenge compelled disclosure of record information.

A record subject must be given prompt notice that legal process has issued, so that he may make a timely challenge to the requested disclosure. The Commission would allow suspension of the notice requirement only under the most compelling circumstances. Specifically, suspension would be justified only when the government can show the court that notice would:

- (i) pose a reasonable possibility that the record sought will be destroyed, or an attempt to destroy it will be made, by the record subject upon whom service of the summons is required, or
- (ii) pose a reasonable possibility that other evidence would be destroyed or become unavailable to government, jeopardizing the investigation; or
- (iii) cause flight from prosecution by the individual upon whom service of the summons is required; or
- (iv) endanger the life or physical safety of any person.

The Commission also adds that these exceptions should not apply to cases in which the record subject has a legitimate expectation of confidentiality recognized by statute or common law; i.e. presumably cases involving medical records. In any case, provisions in the pending legislation allowing for suspension of notice under circumstances other than those set out above, should be deleted.

When an individual challenges compelled disclosure, the burden should be on the government to show reasonable cause that the request is legitimate and the information is relevant. Any lesser standard (i.e. reasonable belief) will increase the likelihood that unnecessary or unfair disclosures will be made. A motion to quash should be granted unless a court specifically finds both "reasonable cause" and that the government's need outweighs the individual's privacy interest. Affidavits and other documents presented by the government in support of dis-

closure should not be filed in camera, which would severely limit an individual's ability to contest the relevance of a proposed disclosure. A court should be given the power to award fees and costs to one who prevails on a motion to quash. Individuals should also be permitted to avail themselves of any existing state procedures for challenging a proposed disclosure to a government agency.

Procedures for limiting delay of notice and for challenging compelled disclosure should extend to all forms of legal process, including administrative subpoenas and subpoenas or summonses issued in connection with proceedings before a grand jury.

Search Warrants

Government access to medical information should be through summons and subpoena rather than search warrant. Obviously no effective right to challenge disclosure pursuant to search warrant can exist since notice is given after the fact. For this crucial reason the Privacy Commission recommended that government access to medical records be limited to other existing forms of legal process, and that notice be suspended only under narrow circumstances.

It is important to note that additional problems are presented when the party named in the warrant (either patient, the medical care facility or both) is not suspected of criminal activity. While the use of a warrant in this instance might

be permissible under the Supreme Court's recent decision in Zurcher v. Stanford Daily, it would be wholly inconsistent with legislation recently introduced to reverse Stanford Daily and prohibit the use of warrants to search innocent third parties.

Redisclosure

The provisions in the various bills allowing a record recipient to redisclose confidential information should be eliminated or drastically altered. The presumption in every case should be strongly in favor of a direct request to the medical facility rather than to a research project, auditor, evaluator or government agency which has already obtained the information. Disclosures to a government agency should only be made pursuant to proper legal process rather than in response to a request from another agency, so as to preserve the record subject's right to challenge each request. Requests for information by other third parties should only be made to the care provider, since they are more likely to give adequate weight to the record subject's privacy interest.

Notice to a Patient of His Rights Under the Act

A new patient must be given notice of both his right of access as well as of the disclosures which may be made without his authorization. Provisions in the bill which require notice only when reasonably possible should be deleted. Additional notifications should be made each time services are provided, if more than a year has passed since the previous notice. Notice should also be given whenever changes are made in the scope of unauthorized disclosures.

Rights of Minors

A minor patient should be given access to medical records concerning treatment he has sought on his own behalf, if state law permits him to obtain such treatment without knowledge or consent of his parents. Access should be limited to patients, and not extended to parents, so as not to discourage minors from obtaining proper treatment in connection with such conditions as venereal disease, drug abuse and pregnancy. Similarly, the minor [ex]patient alone should be permitted to authorize disclosure.

Enforcement and Compliance

(a) Withdrawal of Funds

Substantial compliance with the Act should be a pre-condition of receipt of federal funds under as wide a range of federal programs as possible. H.R. 3444 adopts the most inclusive list of federal programs affected.

(b) Civil Actions

A record subject should be able to bring a civil action for a violation of any provision of the act including violations of the government access provisions. A minimum damage award of \$1,000, as in H.R. 2979, should be established and no cap should be made on recovery for actual damages. Punitive damages should be available in appropriate cases.

(c) Criminal Penalties

Criminal sanctions should be invoked against those who gain access to confidential information under false pretenses, as well as against those who improperly disclose confidential

information or deny a patient access to his record, as under S.503.

Effect on State Law

The Act should not supersede any state laws which are consistent with its provisions and which afford an individual's privacy interest greater protection.

Scope of Service Providers Covered

Any final version of the Act should apply to the broader range of health care providers which would be covered by H.R. 3444.

AMERICAN CIVIL LIBERTIES UNION

Washington Office

July 20, 1979

The Honorable Richardson Preyer
Chairman, Subcommittee on Government
Information and Individual Rights
2344 Rayburn House Office Building
Washington, D.C. 20515

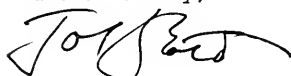
Dear Mr. Chairman:

In connection with my testimony on H.R. 2979 and H.R. 3444 before the Subcommittee on June 14, 1979, I am enclosing the ACLU's detailed comparison of and recommendations concerning the pending House and Senate bills on medical privacy.

I am pleased to continue to assist the Subcommittee in developing the strongest possible legislation in this area, and would be happy to respond to any questions you may have about our study or recommendations.

Best regards,

Yours sincerely,



John H.F. Shattuck
Director

Enc.

cc: Members of the Subcommittee (with enclosure)

600 Pennsylvania Avenue, S.E. Washington, D.C. 20003 (202) 544-1681

John H. F. Shattuck, Director • Jerry J. Berman, Karen Christensen, Legislative Counsel
David E. Landau, Staff Counsel • Laura Murphy, Legislative Representative
Norman Dorsen, Chairperson, Board of Directors • Ira Glasser, Executive Director

AMERICAN CIVIL LIBERTIES UNION

Washington Office

COMPARISON OF AND RECOMMENDATIONS CONCERNING
S. 503, S. 865/H.R. 3444 and H.R. 2979,
LEGISLATION TO PROTECT THE PRIVACY OF MEDICAL RECORDS

Prepared by:

John H.F. Shattuck
Director

Paul Ziëff
Legislative Associate

July 16, 1979

600 Pennsylvania Avenue, S.E. Washington, D.C. 20003 (202) 544-1681

John H. F. Shattuck, Director • Jerry J. Berman, Karen Christensen, Legislative Counsel
David E. Landau, Staff Counsel • Laura Murphy, Legislative Representative
Norman Dorsen, Chairperson, Board of Directors • Ira Glasser, Executive Director

- e. For auditing or evaluation (§ 125).

Note: Disclosure without legal process in any of these instances (c-e, supra) is inconsistent with the principles articulated by the Commission, and the exceptions should be eliminated or narrowed. Nonetheless, they are not as numerous as the broad exceptions to the legal process requirement in S. 503 and S. 865/H.R. 3444.

2. Under S. 865/H.R. 3444 government access without process is permitted:

- a. if there are compelling circumstances affecting the health or safety of a person (§ 202(4)).
- b. if information is "immediately needed" to prevent serious property damage or flight to avoid prosecution (§ 202(12));
- c. pursuant to court rules, if both the government and the record subject are parties (§ 202(13));
- d. for Secret Service or foreign and counter-intelligence purposes. Same procedures as under H.R. 2979 (§ 202(15)). See Note, supra;
- e. if the information is in materials belonging to and sought by any of the uniformed services (§ 202(16)).
Along with the provision allowing such records to be disclosed without authorization, these provisions effectively preclude any expectation of confidentiality on the part of military personnel.
- f. if the information belongs to a correctional authority and is sought by the corrections authority or another agency for purposes of parole, probation, pardon or commutation, or for investigation of an offense committed in a correctional facility (§ 202(17));

- g. if the information belongs to the Veterans Administration and is sought for the purpose of determining or providing benefits (§ 202(19));
- h. if the information is sought by a federal authority for the purpose of processing a claim related to medical services (§ 202(20)).
- i. for a government public health investigation, for a government investigation of the facility or for a federal, state, or local government audit or evaluation (§ 202(5A)).
- j. to carry out a program under Title V, part B of Title XI, Title XVIII or Title XIX of the Social Security Act, or other Government Program providing payments to, or concerned with activities of the facility or to conduct an investigation concerning fraud, abuse or waste under those programs (§ 202(5B)).
- k. pursuant to a formal request by any federal authority as long as:
 - i. no administrative or subpoena authority appears to be available;
 - ii. the request is authorized by agency regulations;
 - iii. there is reason to believe that the medical information is relevant to a legitimate law enforcement inquiry;
 - iv. a copy of the request is sent to the individual granting him a right to challenge the request (§§ 202(10); 206).

Note: While the expansion of categories is in itself objectionable, the last provision allowing for disclosure upon a mere formal request is most destructive of the individual's legitimate expectation of confidentiality. Not only does it dangerously broaden the ambit of government access far beyond that permitted under H.R. 2979 and the Commission recommendations, but the "reason to believe" standard is far more likely to result in inappropriate disclosures than is the "reasonable cause" standard recommended by the Commission and adopted by H.R. 2979.

3. Under S. 503 government access without legal process is permitted:
 - a. In the event of a bona fide medical emergency (§ 206).
 - b. Pursuant to court or administrative rules (§ 210(b)).
 - c. If the information is sought by the GAO pursuant to an investigation, proceeding, examination or audit directed at a government agency (§ 210(f)).
 - d. If the information is sought in connection with a lawful proceeding, investigation, examination, or inspection directed at the service provider in possession of such information or at a legal entity which is not a patient or former patient (§ 210(d)).
 - e. If for Secret Service or foreign and counter-intelligence purposes (§ 211(a)). See Note, supra.
 - f. If the government authority determines that delay in obtaining records would create imminent danger of physical injury to any person, serious property damage, or flight to avoid prosecution.

As under H.R. 2444, the agency must file a signed statement setting forth the grounds for the emergency access (§ 211(b)).

g. For purposes of audit or evaluation (§ 206(b)(3)).

h. Pursuant to a formal request. Same requirements as under H.R. 3444 (§ 206(b)(10)).

B. Compulsory Legal Process

Only if an individual is given an opportunity to challenge inappropriate invocation by government of legal process will any congressionally created expectation of confidentiality have real meaning. Therefore, the Privacy Commission recommended that an individual, in defense against compelled production of a medical record, be permitted to:

- a. challenge the scope and relevance of the summons and subpoena and to require from the government clear proof of a reasonable relationship of the record to the investigation, prosecution or civil action in furtherance of which the process was issued, before a court may order disclosure and
- b. to assert in protection of the record the protections of the First, Fourth and Fifth Amendments.

At the very least the Commission recommends that the government be forced to establish reasonable cause to believe that the record is relevant to prosecution of a violation of law before the legitimate expectation of the individual can be overridden. Naturally, in order to exercise the right to challenge compulsory

disclosure, an individual must be given prompt notice of the fact that process has been served on the medical care provider.

In order to minimize the need for frequent challenges and to limit the potential for abuse that presently lies in the broad power of administrative, judicial and grand jury process, the Commission recommends that process to compel disclosure issue only under certain carefully defined circumstances.

Each of the three bills departs from the principles adopted by the Commission in some respect. However, the provisions regarding compulsory process incorporated in H.R. 2979 are far less destructive of the individual's privacy interest than are those of S. 503 and H.R. 865/H.R. 3444.

1. State and Federal Administrative Subpoenas and Summons, and Judicial Subpoenas

All three bills allow for disclosure pursuant to state and federal legal process, but substantial variation exists with regard to three major areas: Standards; Notice Requirements; and Procedures for Challenging compelled Disclosure.

a. Standards (See S. 503 § 207(a)(1); H.R. 3444 § 203(1); H.R. 2979 § 141(a)(1))

Only H.R. 2979 adopts the Commission recommendation that government access be allowed when there is reasonable cause to believe that the record will produce information relevant to a legitimate law enforcement inquiry. S.865/H.R. 3444 and S. 503 require only that there be reason to believe that the informa-

tion sought is relevant to a legitimate law enforcement inquiry. This standard, in that it is more easily satisfied, is also more likely to lead to inappropriate disclosures.

- b. Notice Requirement (See S. 503 § 207(b); H.R. 3444 § 208; H.R. 2979 § 141(c))

Each of the bills requires that notice of legal process be promptly sent to the medical-record subject, no later than the time that service is made on the recordkeeper. This requirement is incorporated in the recommendations of the Commission, and is necessary to effectuate the right to challenge compelled disclosure.

However, each of the bills establishes procedures through which a government agency may, with the court's permission, delay such notice, with the effect that the right to challenge is nullified. While the range of circumstances under which a delay will be granted is defined too broadly in all of the bills, the procedures for securing a delay are particularly troublesome under S. 865/H.R. 3444 and S. 503. A delay will be granted under H.R. 2979 only if

- i. there is reasonable cause that the information is relevant and
- ii. the government's need for the record requested outweighs the individual's privacy interest. [A third prerequisite is discussed below.] Under S. 865/H.R. 3444 and S. 503,

"reason to believe" that the information is relevant is sufficient, and the Court is not required to balance the government's need to know with the individual's privacy interest. This balancing requirement provides an important safeguard against unnecessary intrusions as it gives the court an opportunity to consider factors such as alternative sources of similar information available to the agency and the substantiality of the intrusion.

In addition to these requirements a court will grant delay under each of the bills only if there is reasonable cause (or "reason to believe" under S. 865/H.R. 3444 and S. 503) that notice will result in

- i. endangering life;
- ii. flight from prosecution;
- iii. tampering with evidence;
- iv. intimidation of potential witnesses or
- v. will otherwise seriously jeopardize an investigation or official proceeding or unduly delay a trial or ongoing official proceeding.

This last category is far too vague and broad to be consistent with an individual's right to control disclosure of personal medical records.

The duration of the delay in all the bills is normally to 90 days, with an opportunity to seek an extension retained by the government agency. However,

both S. 865/H.R. 3444 and S. 503 allow the court to make the delay indefinite if the court finds that notice may endanger the life of the record subject or individuals associated with him. No provisions are made for lifting such an indefinite delay, and it is unlikely that an agency will, on its own, take the initiative to do so. In light of the fact that provisions for seeking extensions are made in these bills, the fact that the only party with an incentive to terminate the delay (i.e. the individual) is unaware of its existence makes the need for periodic court review of extension applications essential.

- c. Procedures for Challenging Compelled Disclosure
See S. 503 § 207(f-j); S. 865/H.R. 3444 § 209;
H.R. 2979 § 142)

An individual has a limited time after receiving notice of service to the record keeper during which he may file a motion to quash the summons or subpoena. Under H.R. 2979 he must do so within fourteen days of the date of service, while under S. 865/H.R. 3444 and S. 503 he must file within 10 days of service or 14 days of the mailing of the notice. After the motion is filed the government agency may file affidavits or sworn documents supporting the validity of legal process. Only H.R. 2979 provides for the filing of counter-affidavits by the individual seeking to quash a subpoena or summons. Not only do S. 865/H.R. 3444

and S. 503 fail to provide for counter-affidavits but they also allow the government agency to file its response to the motion in camera if it includes in its response the reasons which make in camera review appropriate. In camera review, of course, will make it difficult for an individual to contest the relevance of the records to the government investigation. S. 865/H.R. 3444 and S. 503 also hurry the process more than H.R. 2979, in that the court's determination is to be made within seven days of the government's response. H.R. 2979 allows ten days for resolution of the dispute.

The most glaring deficiencies in the challenge procedures of S. 865/H.R. 3444 and S. 503 lie in the standards which are to be used by the court in considering the motion. Under H.R. 2979 the court can deny the motion to quash only if it finds there is reasonable cause to believe that the law enforcement inquiry is legitimate and that the records sought are relevant. In contrast, S. 865/H.R. 3444 and S. 503 allow the court to deny the motion as long as there is a "demonstrable reason to believe" that the inquiry is legitimate and a "reasonable belief" that the information sought is relevant. As the Commission notes, the burden should be on the government to justify the breach of the individual's expectation of

confidentiality. The record subject should be able "to require from the government clear proof of the reasonable relationship" of the information to the particular investigation for which it is sought. While H.R. 2979 is consistent with these principles, S. 865/H.R. 3444 and S. 503 are not. Under these bills, the individual must carry the burden rather than the government. This is reflected in the lower standards which must be met for disclosure to be allowed (i.e., demonstrable reason to believe); and in the fact that an individual seeking to challenge legal process is charged with stating in the motion to quash why the confidential information is not relevant to the law enforcement inquiry.

Under H.R. 2979 even if the inquiry is legitimate and the information is relevant, the Court must grant the motion to quash if it finds that the individual's privacy interest outweighs the government authority's need for the record. No comparable safeguard of the individual expectation of confidentiality is incorporated in S.865/H.R. 3444 or S. 503. H.R. 2979 is also the only bill that allows the court to assess against a federal authority the litigation costs incurred by an individual who "substantially" prevails in a challenge to compelled disclosure. Not only is this provision necessary to encourage an individual to exercise his rights, but it might also discourage

agencies from making frivolous requests.

It should be noted that both S. 865/
H.R. 344 and S. 503 expressly state that a motion to quash must be granted if it is shown that the requesting agency has not substantially complied with the provisions of the bill. No similar basis for granting the motion is expressly provided for in H.R. 2979.

All three bills provide that these procedures constitute the sole judicial remedy available to an individual seeking to oppose disclosure of records under the bill. To the extent that state law provides better protection of an individual's expectation of confidentiality, there is no justification for denying an individual his right to take advantage of existing state remedies.

None of the bills require that an administrative summons be issued only by officials who exercise supervisory authority, as is recommended by the Commission. The Commission noted that administrative summonses are commonly issued by individuals without such authority, and that limiting the range of people capable of compelling disclosure of medical records will provide an important safeguard against inappropriate requests.

S.503 exempts from coverage administrative subpoenas issued by an administrative law judge in an adjudicatory proceeding subject to Section 554 of

Title 5, U.S.C. to which the government authority and the record subject are parties. Consequently in these situations an individual will have no right to receive notice or to challenge the compelled disclosure (§ 210(c)).

As noted earlier both S. 865/H.R. 3444 and S. 503 allow for disclosure pursuant to formal written request in cases where no summons or subpoena power exists. Disclosure in these cases can be challenged in the same way as can disclosure pursuant to legal process. However, only S. 865/H.R. 3444 allows an agency to seek a delay of the notice obligation where the government access is sought by formal request. Considering the extent to which the formal request provision is in itself subject to abuse, the opportunity to defer notifying the individual makes it completely inconsistent with protection of an individual's privacy interest (see S.503 § 209, S. 865/H.R. 3444 § 206).

2. Subpoena or Summons Issued in Connection with Proceedings Before a Grand Jury (See S. 503 § 210(e); S. 865/H.R. 3444 §202(18); H.R. 2979 §141-2).

As recommended by the Privacy Commission, H.R. 2979 provides the same protections to an individual (i.e., notice, right to challenge) when his records are sought pursuant to a subpoena or summons issued in connection with a grand jury proceeding. However, no such protections are provided under S. 865/H.R. 3444 and S. 503. Here again, these bills leave substantial gaps tending to undermine the legitimate expectation of confidentiality which it is the

fundamental purpose of the legislation to establish.

The Commission has also made recommendations concerning the disposition of records obtained by a grand jury. These recommendations grow out of a desire to minimize the potential for abuse of the grand jury's broad powers, and to prevent the government agencies from using information obtained in a grand jury investigation for unrelated purposes. Essentially, the recommendations require that information be used only for the purposes for which it was procured, and that it either be returned to the record-keeper, destroyed or maintained by the government only in the sealed record of the grand jury. All three bills adopt these recommendations almost entirely, with one significant departure. All allow a government authority to maintain the information (other than in the sealed grand jury record) if the medical record has been used in the prosecution of a crime for which the grand jury issued an indictment or presentment (see S. 503 § 218; S. 265/ H.R. 3444 § 212; H.R. 2979 § 131(b)).

Limiting maintenance of the information to a grand jury record as recommended by the Privacy Commission would allow a second grand jury to continue the investigation (should the first grand jury expire before an indictment is issued). It would also avoid the risk that the information will end up in an investigator's file, and be used for purposes unrelated to the grand jury investigation.

3. Search Warrants (see S. 503 § 208; S. 865/H.R. 3444 § 204; H.R. 2979 §141(b)).

All three bills provide for acquisition of medical records by the government through a properly issued search warrant. Notice and a copy of the search warrant must be sent to the individual within 30 days of service of the warrant under H.R. 2979. Notice need not be made for 90 days under both S. 865/H.R. 3444 and S. 503. Obviously no effective right to challenge disclosure pursuant to a search warrant can exist since notice is given after-the-fact. While the probable cause standard which must be met before a warrant is issued provides some protection against unnecessary disclosures, it is no substitute for the right to challenge compelled disclosure before it is made. There will be cases in which probable cause exists and the warrant is issued in spite of the fact that the government's need for the information does not outweigh the individual's privacy interests. Mandatory use of a subpoena, rather than a warrant, would be more protective of an individual's expectation of confidentiality.

Notice of the search warrant can be delayed with the court's permission for up to 90 days under H.R. 3444 and up to 180 days under S. 503 with provisions for extensions in both bills. [It is somewhat unclear whether delay would be permitted under H.R. 2979.]

Note that additional problems are presented when the party named in the warrant (i.e. the medical care facility)

is not suspected of criminal activity. While this is consistent with the recent Supreme Court decision concerning third party searches (Zurcher v. Stanford Daily), it would be inconsistent with pending legislation to prohibit the use of third party search warrants. The legislation reflects a widely shared concern regarding the impropriety of subjecting an innocent party to a surprise search and seizure.

V. REDISCLASURE

Whatever protection an individual has as a result of restrictions on the ability of government agencies, evaluators, auditors, and researchers to gain access to medical records, it is necessarily undermined if once obtained, the information is subject to redisclosure. As the Commission points out, a tremendous potential for abuse lies in the fact that information in the hands of one agency frequently becomes a general governmental resource and freely flows to other agencies.

Effective protection of an individual's privacy interest demands stringent limitations on a medical record recipient's ability to redisclose. The presumption in all cases should be in favor of obtaining the record directly from the medical care provider in accord with the provisions of the Act. Only the medical facility stands to lose federal funding in the event of improper disclosures which are deemed to constitute a failure to substantially comply with the bill. In addition, the care provider is likely to give more weight to an individual's privacy interest than will a recipient of the record, in deter-

mining whether to make a permissible unauthorized disclosure, not required by law. H.R. 2979 explicitly states that the terms of the bill describing disclosures which do not require authorization, should not be construed as requiring a service provider to disclose information, not otherwise required by law. Discretionary decisions of this sort which so clearly implicate an individual's privacy interest are best left to the care provider which has the most at stake (federal funds) and the greatest institutional commitment to the welfare of the record subject. The provisions in the three bills allowing for redisclosure by researchers, auditors and evaluators have been discussed above (see Section on Unauthorized Disclosures; Research, Audit and Evaluations above).

Each of the bills allow for redisclosure by government agencies. An additional objection to allowing such transfer of information from one agency to another is that the individual is deprived of his right to challenge disclosure. When information is transferred rather than obtained through legal process, the individual cannot contest the relevance of the information in an effort to prevent an inappropriate or unnecessary disclosure. In the event of a redisclosure that is in violation of the Act, any relief comes only after the individual's privacy interest has already been compromised. Redisclosure is permitted under each of the bills under a broad range of circumstances and the process is dangerously routine.

Under both S.865/H.R. 3444 and S. 503 transfer of confidential information to another government agency is permissible whenever the transferring authority certifies in writing that there is reason to believe that the information is relevant to a legitimate law enforcement inquiry within the jurisdiction of the receiving authority. This would apply to information acquired under emergency access conditions or pursuant to legal process or formal written request (see S. 503 § 214; S. 865/H.R. 3444 § 210).

Under S.865/H.R. 3444 notice of the transfer need not be given to the record subject for fourteen days, and permission to delay notice can be obtained from the court by either the transfer or transferee agency. Under S. 503 no notice of the transfer need be given at all.

Under H.R. 2979 a government agency which obtains confidential information is free to redisclose it (a) where necessary to fulfill the purpose for which the record was obtained; or (b) for any of the purposes for which disclosure can originally be made without authorization (e.g. health research, audits and evaluations, health and safety, law enforcement, etc.). (See H.R. 2979 § 124-§130.) No notice of such redisclosure need be given.

An individual's privacy interest is seriously jeopardized when the potential exists for legitimate acquisition by a government authority to be so routinely followed by an improper transfer to another agency.

VI. NOTICE TO A PATIENT OF HIS RIGHTS UNDER THE ACT

The Commission recommends that notice be given to a patient by a service provider of the categories of disclosures which may be made without his authorization. A patient should also be informed of his right to inspect his medical record.

The provisions of H.R. 2979 provide for the most complete and frequent notice. Notice of both access rights and unauthorized disclosure categories are made when services are first provided, when services are first provided more than a year after the previous notice, and when services are first provided after a substantial change has been made in the notice (see § 113).

Under S. 503 notice need only be given when confidential information is first recorded, and when services are first provided, and then only when the provider reasonably can do so under the circumstances. No such "reasonableness" qualification is placed on the duty of the provider to give notice under H.R. 2979 (see § 213).

Under S. 865/H.R. 3444 provision is made for giving notice of unauthorized disclosure categories, and of procedures for learning of unauthorized disclosures, but notice of the right to access is not provided for. Notice need only be given where reasonably possible, when services are first provided and upon request (see § 103).

VII. RIGHTS OF MINORS

In order to protect the confidentiality of the medical care relationship, the Privacy Commission recommends that a minor patient be given access to medical records concerning treatment he has sought on his own behalf, if state law permits him to obtain such treatment without the knowledge or consent of his parents. Access should be limited to patients, and not extended to parents, so as not to discourage minors from obtaining proper treatment in connection with such conditions as venereal disease, drug abuse and pregnancy. Similarly, the minor [ex]patient alone should be permitted to authorize disclosure.

The three bills deal with this issue differently. H.R. 2979 is most at odds with the Commission approach. Under H.R. 2979 the rights of an individual under the age of majority are to be exercised by a parent or guardian. Essentially there is no expectation of confidentiality for minors, at least vis-a-vis his parents (see § 103). S.865/H.R. 3444 takes the view that rights of minors will be exercised by a parent or guardian except in those situations prescribed by the Secretary in which it is in the interests of the minor to exercise his own rights (see § 310(10)). S. 503 places no restrictions on the age of a [ex]patient seeking access. With respect to authorization of disclosure, minors over the age of 12 can do so on their own (see §§ 203(d), 204(b)). There is no indication in S. 503 that these rights are shared with parents. Consequently the provisions of S. 503 dealing with the rights of minors are preferable over the others, with those of H.R. 2979 leaving the most to be desired.

VIII. ENFORCEMENT AND COMPLIANCE

- a. Withdrawal of Funds (See S. 503 § 216(c); S. 865/H.R. 3444 § 106(a); H.R. 2979 § 151).

Substantial compliance with the provisions of the Act is a pre-condition to continued government financial support of the medical care provider under each of the bills. However, the number of funding sources contingent on substantial compliance varies somewhat. Under H.R. 2979, only funding under Titles XVIII and XIX of the Social Security Act would be affected. S. 503 adds to these, federal support under subchapter XI of the Public Health Service Act, and S. 865/H.R. 3444 also includes funding under Title V of the Social Security Act, the Community Mental Health Centers Act, the Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment and Rehabilitation Act of 1970, and the Drug Abuse Offense and Treatment Act of 1972.

- b. Civil Actions (See S. 503 § 216(a); S. 865/H.R. 3444 § 302, H.R. 2979 § 153)

Each of the bills provide for civil actions to be brought against medical care facilities, researchers, auditors, government authorities and others who violate terms of the Act. However, H.R. 2979 does not provide for a civil action to be brought by one aggrieved of a violation of the government access provisions. Minor variations in the bills exist as to damage provisions.

H.R. 2979 allows recovery for actual damages or \$1,000 whichever is greater. As under the other bills, a court may award attorneys fees and grant equitable relief when appropriate. Punitive damages are also available in appropriate cases. H.R. 3444 places a \$10,000 cap on general damages and it is unclear whether punitive damages are available. No cap is placed on damages under S. 503 and punitive damages may be granted in cases where the violation was willful or grossly negligent.

- c. Criminal Penalties (See S. 503 § 216(b), S. 865/H.R. 3444 § 301, H.R. 2979 § 152)

Under each of the bills, acquisition of medical information from a health facility under false pretenses is a misdemeanor and carries a \$10,000 fine and/or a one year prison sentence. Only S. 503 imposes a similar criminal penalty on one who either discloses confidential information or fails to grant a patient access to his complete health record.

- IX. EFFECT ON STATE LAW (See S. 503 § 220, S.865/H.R. 3444, § 308, H.R. 2979 § 102)

S. 865/H.R. 3444 will override state laws to the extent that those laws are inconsistent with the Act. S. 503 would pre-empt any state laws less stringent than the terms of the bill.

Only H.R. 2979 would generally supersede state or local laws governing the confidentiality of medical records maintained by medical care facilities covered by the bill. This may in some cases reduce the protections afforded a record subject if state laws are stronger than H.R. 2979. However, exceptions are made, such that H.R. 2979 will not supersede state and local laws restricting access to records relating to drug and alcohol abuse and mental health treatment.

X. SCOPE OF SERVICE PROVIDERS COVERED

There is considerable variation in the range of medical care providers which will have to comply with the different bills. The narrowest coverage is under H.R. 2979, and the broadest under S.865/H.R. 3444.

H.R. 2979 only applies to:

- (a) hospitals, skilled nursing facilities or intermediate care facilities approved by the Secretary to participate in Title XIX of the Social Security Act;
- (b) other entities for which approval or certification to participate in Title XVIII or XIX is needed and has been granted, but only with respect to such provisions of the Act as the Secretary specifies by regulation;
- (c) an entity of the United States which is a hospital, skilled nursing facility, or intermediate care facility.

S. 502 is similar to H.R. 2979 but modifies it as follows: adds ambulatory care facility to: (a) above; incorporates (b) as is; does not include (c); but adds: health maintenance organizations, medical groups, or individual

practice associations as defined in Title XIII of the Public Health Service Act, which have received a federal grant, loan guarantee or contract pursuant to the Act, but only with respect to the provisions specified by the Secretary.

S.865/H.R. 3444 applies to any facility (except state or local government facilities which do not receive federal funds) that is primarily engaged in providing:

- (a) inpatient medical and rehabilitative services to injured, disabled and sick individuals;
- (b) health-related services to individuals in the facility who because of their mental or physical condition require such services (above the level of room and board); or
- (c) health-related services to outpatients, if the facility is receiving funds from appropriations authorized by the Public Health Service Act, Title V of the Social Security Act, the Community Mental Health Centers Act, the Comprehensive Alcoholism Abuse and Alcoholism Prevention, Treatment and Rehabilitation Act of 1972; so long as the facility is made subject to the provisions of the Act by regulations of the Secretary.

Important Note: The provisions of S.865/H.R. 3444 requiring that a facility provide a patient access to his medical records and opportunity to correct them as well as those limiting the disclosures which can be made, apply only to those service providers described above. However, the provisions concerning government access would allow the government to secure record information in the prescribed manner from any person or other entity that provides health services to individuals (see §§202; 309(3)). This presents a serious problem in that the government can obtain records which the patient has no opportunity to inspect or correct. This not only is patently unfair, but it defeats the fundamental purposes of the legislation itself. It allows a health service provider to disclose confidential information to a government agency without requiring the provider to grant access to the patient himself. The potential for harm to an individual record subject that exists when the information is inaccurate is compounded by other provisions in S. 865/H.R. 3444 which allow a government agency to redisclose this information. Fairness demands that the scope of providers from whom the government can obtain confidential information be no greater than the scope of providers who must comply with the other provisions of the bill.

COMPARISON OF AND RECOMMENDATIONS CONCERNING
S. 503, S. 865/H.R. 3444 and H.R. 2979,
LEGISLATION TO PROTECT THE PRIVACY OF MEDICAL RECORDS

The problem of medical privacy is addressed in a recent report issued by the President's Privacy Protection Study Commission. A set of comprehensive recommendations have been developed by the Commission which if adopted should accomplish three related objectives. They are designed to (a) minimize intrusiveness (b) maximize fairness and (c) create a legitimate, enforceable expectation of confidentiality.

The central elements of the Commission's recommendations are as follows:

- (a) creation of a right of access to one's medical records and an opportunity to correct inaccuracies in the record;
- (b) establishment of a general rule that any disclosures will be limited to those authorized by the record-subject, with only a few carefully defined exceptions justified by a compelling societal interest in disclosure;
- (c) limitations on the content of disclosures and the uses to which the disclosed information is put which reflect the purpose for which the disclosure is made;
- (d) requiring that requests by government agencies for medical record information be made only through recognized legal process; and
- (e) providing a record subject with an opportunity to challenge

government access on the basis of the relevance and importance of the requested information.

The recommendations represent an important step in the direction of creating an enforceable expectation of confidentiality in the doctor-patient relationship. The three bills presently before Congress (S.503, S.865/H.R. 3444 and H.R. 2979) adopt, in varying degrees, some of the recommendations of the Commission. As such, they reflect a recognition of the importance that an individual's privacy interest holds in our society as well as of the need to protect that interest from the destructive tendencies of ever increasing collection and dissemination of personal information. While praiseworthy in this respect, the bills depart in substantial respects from recommendations offered by the Commission and in so doing dilute the positive impact on the confidentiality of the medical care relationship that the bills are designed to have. This report considers each of the bills in some detail, taking note of the deviations between the proposed legislation and the recommendations of the Commission. Each bill has strengths and weaknesses. To be worth enacting, any final version must reflect the strengths and eliminate the weaknesses.

Summary

Patient Access

Medical care providers should be required to respond to either written or oral requests for access to medical records. Providers should be required to develop a sliding scale so that

charges of copying one's record are never so high as to discourage exercise of the right. Any standard to be used by a care facility in determining whether to deny direct access and to require disclosure of sensitive information to a third party designated by the individual, should not be so vague as to leave a service provider broad discretion.

Correction of Medical Records

Medical facilities should be required to make a prompt response to a request to correct a medical record. Thirty days would provide an adequate amount of time to do so. Provisions should be made for appeal of a refusal to modify the record as requested. Should the correction be denied, the health care facility should at the request of the record subject, be required to submit to prior recipients of the disputed information a copy of the requestor's statement of disagreement, if one is filed. Similarly any corrections and amendments in the record should be submitted to prior recipients of the inaccurate record, if requested by the record subject.

Authorization for Disclosures

Any authorization of a disclosure should be in writing and should be specific as to the content and purpose of the disclosure. An authorization should contain an expiration date and should not be effective for more than one year.

Unauthorized Disclosures

In order to protect an individual's expectation of privacy, unauthorized disclosures should be severely limited. The Privacy

Commission recommended a sharply limited number of circumstances under which unauthorized disclosures might be permitted. The Commission's recommendations strike a balance between the individual's right to personal privacy and society's needs for information about his medical condition. Each of the bills substantially expands the scope of permissible unauthorized disclosure. This expansion is dangerous and unacceptable. Provisions allowing disclosure for research purposes should incorporate strong safeguards to minimize the potential for abuse. The provisions providing for unauthorized disclosure of information for law enforcement, foreign intelligence and Secret Service purposes as well as those relating to operation, evaluation and investigation of government funded programs, should be drawn far more narrowly. Many of the new categories do not seem to involve circumstances compelling enough to justify the erosion of an individual's expectation of confidentiality that necessarily follows from a wide range of permitted unauthorized disclosure.

The Secretary should prescribe security standards with respect to the use and maintenance by researchers, auditors and evaluators of medical record information disclosed without authorization.

Government Access

In order to protect the individual's expectation of privacy, requests by government agencies for medical record information

should be made only through recognized legal process.

Provisions for access by a mere formal written request and other exceptions to the legal process requirement--especially broad exceptions made for law enforcement, foreign intelligence, Secret Service, and government program operation purposes--all undermine the protections afforded a record subject by other provisions in the bills. Consequently, they should be eliminated or drawn far more narrowly.

Only under the most compelling circumstances, if at all, should an individual be deprived of an opportunity to challenge compelled disclosure of record information. Therefore, a record subject must be given prompt notice that legal process has issued, so that he may make a timely challenge to the requested disclosure. The Commission would allow suspension of the notice requirement only under the most compelling circumstances. Specifically, suspension would be justified only when the government can show the court that notice would:

- (i) pose a reasonable possibility that the record sought will be destroyed, or an attempt to destroy it will be made, by the record subject upon whom service of the summons is required; or
- (ii) pose a reasonable possibility that other evidence would be destroyed or become unavailable to government, jeopardizing the investigation; or
- (iii) cause flight from prosecution by the individual upon whom service of the summons is required; or

(iv) endanger the life or physical safety of any person.

The Commission also adds that these exceptions should not apply to cases in which the record subject has a legitimate expectation of confidentiality recognized by statute or common law; i.e., presumably cases involving medical records. In any case, provisions in the pending legislation allowing for suspension of notice under circumstances other than those set out above, should be deleted.

When an individual challenges compelled disclosure, the burden should be on the government to show reasonable cause that the request is legitimate and the information is relevant. Any lesser standard (i.e., reasonable belief) will increase the likelihood that unnecessary or unfair disclosures will be made. A motion to quash should be granted unless a court specifically finds both "reasonable cause" and that the government's need outweighs the individual's privacy interest. Affidavits and other documents presented by the government in support of disclosure should not be filed in camera, which would severely limit an individual's ability to contest the relevance of a proposed disclosure. A court should be given the power to award fees and costs to one who prevails on a motion to quash. Individuals should also be permitted to avail themselves of any existing state procedures for challenging a proposed disclosure to a government agency.

Procedures for limiting delay of notice and for challenging compelled disclosure should extend to all forms of legal

process, including administrative subpoenas and subpoenas or summonses issued in connection with proceedings before a grand jury.

Administrative summonses should only be issued by officials who exercise supervisory authority within the agency.

Search Warrants

Government access to medical information should be through summons and subpoena rather than search warrant. Obviously no effective right to challenge disclosure pursuant to search warrant can exist since notice is given after the fact.

It is important to note that additional problems are presented when the party named in the warrant (either the patient, the medical care facility or both) is not suspected of criminal activity. While the use of a warrant in this instance might be permissible under the Supreme Court's recent decision in Zurcher v. Stanford Daily, it would be wholly inconsistent with legislation recently introduced to reverse Stanford Daily and to prohibit the use of warrants to search innocent third parties.

Redisclosure

The provisions in the various bills allowing a record recipient to redisclose confidential information should be eliminated or drastically altered. The presumption in every case should be strongly in favor of a direct request to the medical facility rather than to a research project, auditor, evaluator or government agency which has already obtained

the information. Disclosures to a government agency should only be made pursuant to proper legal process rather than in response to a request from another agency, so as to preserve the record subject's right to challenge each request. Requests for information by other third parties should only be made to the care provider, since they are more likely to give adequate weight to the record subject's privacy interest.

Notice to a Patient of His Rights Under the Act

A new patient must be given notice of both his right of access as well as of the disclosures which may be made without his authorization. Provisions in the bill which require notice only when reasonably possible should be deleted. Additional notifications should be made each time services are provided, if more than a year has passed since the previous notice. Notice should also be given whenever changes are made in the scope of unauthorized disclosures.

Rights of Minors

A minor patient should be given access to medical records concerning treatment he has sought on his own behalf, if state law permits him to obtain such treatment without knowledge or consent of his parents. Access should be limited to patients, and not extended to parents, so as not to discourage minors from obtaining proper treatment in connection with such conditions as venereal disease, drug abuse and pregnancy. Similarly, the minor [ex]patient alone should be permitted to authorize disclosure.

Enforcement and Compliance(a) Withdrawal of Funds

Substantial compliance with the Act should be a precondition of receipt of federal funds under as wide a range of federal programs as possible.

(b) Civil Actions

A record subject should be able to bring a civil action for a violation of any provision of the Act including violations of the government access provisions. A minimum damage award of \$1,000 should be established and no cap should be made on recovery for actual damages. Punitive damages should be available in appropriate cases.

(c) Criminal Penalties

Criminal sanctions should be invoked against those who gain access to confidential information under false pretenses, as well as against those who improperly disclose confidential information or deny a patient access to his record.

Effect of State Law

The Act should not supersede any state laws which are consistent with its provisions and which afford an individual's privacy interest greater protection.

Scope of Service Providers Covered

Any final version of the Act should apply to a broader range of health care providers. However, the scope of care providers from whom the government can obtain medical records should be no greater than the scope of providers who are covered by the other provisions of the bill (i.e., provisions regarding patient access and correction, limited disclosure, etc.). The government should not be allowed to obtain information which the patient cannot inspect and correct. To allow this, as does the Administration proposal, is both unfair and inconsistent with the purposes of the legislation.

I. PATIENT ACCESS TO AND RIGHT TO CORRECT MEDICAL RECORDS.
(See S.503 § 203; S. 865/H.R. 3444 §101; H.R. 2979 § 111)

A. Patient Access

The Commission recommends that an individual who is the subject of a medical record maintained by a medical care provider, or another responsible person designated by the individual, be allowed to have access to that medical record. In addition, procedures for correcting mistakes in the record should be established by care providers. These recommendations flow from basic notions of fairness, as well as from a recognition of the harm that can befall an individual as a consequence of inaccurate, obsolete, or incomplete medical record information.

1. Nature of Request

A medical care provider must respond to an oral as well as a written request for access under S. 503, while under H.R. 2979 the provider may require a written application before it is under any obligation to respond. No qualification of the term "request" is made in S. 865/H.R. 3444 so apparently an oral request would suffice.
Any bill enacted should obligate care providers to respond to both written and oral requests.

2. Response Time

A care provider has 30 days to respond to a request under both S. 503 and H.R. 2729; while under H.R. 3444 a provider has 20 working days during which to respond.

3. Reasonable Fee

All of the bills stipulate that medical care facilities may not charge for inspection of the records, but may impose a reasonable charge for providing a copy of the record (not to exceed the amount charged third parties). As the Privacy Commission report notes, reasonable charges may range from \$10 to several hundred dollars, and therefore the Commission urges providers to develop sliding fee schedules so that a patient's right to access is not contingent on his financial position. However, none of the bills provide for such a mandatory sliding scale.

4. Indirect Access

The Commission Report suggests that under very limited circumstances a medical care provider may be justified in denying direct access to an individual because of the potentially harmful nature of the information. In these cases disclosure must instead be made to a reasonable third party designated by the individual. This general approach is adopted by all three bills with some variations.

a. Standards: When denial of direct access is justified:

°Under S.503: When a service provider determines that disclosure would be detrimental to the requestor.

°Under H.R. 3444: When the facility determines that disclosure would be likely to be sufficiently harmful to the individual or to

another person so as to outweigh the desirability of applying the direct access provision of the bill.

*Under H.R. 2979: When the facility determines that the inspection might reasonably be expected to cause sufficient harm to the individual so as to outweigh the desirability of permitting access. Criteria for making this determination are to be issued by the Secretary of HEW.

The standard most protective of the rights of the record-subject would combine elements of each of the above and would allow a facility to deny direct access only when a service provider determines that disclosure "would be" [S. 503] "sufficiently harmful to the individual. . . so as to outweigh" [H.R. 3444] the desirability of permitting access. As under H.R. 2979 the Secretary should be required to promulgate guidelines to assist service providers in making this determination. Such a standard would minimize the discretion of a service provider in making this determination while specifically requiring a balancing of the important competing interests, before direct access is denied.

b. Eligible Third Party Designee

In the event that direct access is refused, the records must be made available to a third party designated by the [ex]patient. Both H.R. 2979 and H.R. 3444 allow for disclosure to any "appropriate

person" (as defined in regulations of the Secretary) designated by the individual. S. 503 provides for disclosure to an "authorized representative" appointed by the individual as long as the representative complies with those procedures for authorizing disclosure of medical records normally carried out by the individual (see S. 503 §§ 203(c); 205(a)).

B. Correction of Medical Records (See S.503 § 203, H.R. 3444 § 102; H.R. 2979 § 112)

All of the bills adopt the general framework presented by the Commission for processing requests to correct inaccuracies in a medical record.

The medical care provider must respond to such a request either by granting it, or by informing the requestee; of the reasons for denial, of any procedures for review that might exist, and of the individual's right to file a statement outlining the nature of and reasons for his disagreement with the record. This statement becomes a permanent part of the service provider's record and will be disclosed to any persons receiving the disputed information in the future. Only H.R. 3444 imposes on the service provider an obligation to send the [ex]patient's statement of disagreement to previous recipients of the disputed information.

While H.R. 3444 is preferable in this request, it is deficient in another respect. It gives a service provider 90 days to respond to a request to make a correction. If the individual is requesting a correction because he is about to

authorize disclosure to a third party for employment or insurance purposes, this three month lag can be a serious problem. H.R. 2979 is preferable in that it requires a response within 30 days. S. 503 provides no time limit but indicates that procedures for processing requests to correct medical records will be developed by service providers in accord with regulations promulgated by the Secretary. The 30 day time limit under H.R. 2979 is adequate and should be written into any final legislation.

None of the bills require a medical care provider to develop a review mechanism to be utilized by one refused a correction. A review procedure would provide an important safeguard against unfair or arbitrary refusals to correct a record upon request.

II. DISCLOSURE PURSUANT TO AUTHORIZATION (See S. 503 § 205; S.865/H.R. 3444 § 105(d); H.R. 2979 § 115)

The Privacy Commission notes that in order to create a legitimate expectation of confidentiality it is necessary to place effective control over the disclosure of medical information in the hands of the record subject. In order to be sure that consent to any given disclosure is both informed and freely given, it is necessary that the authorization be specific both as to the amount and type of information that is disclosed, as well as to the conditions under which disclosures are made.

Each of the bills requires a written consent signed by the individual before a disclosure pursuant to authorization. Each also requires that the party disclosing the information, as

well as the party authorized to receive it, be identified either specifically or generally in the writing. Only S. 503 requires that both the content and the purpose of the disclosure be specified in the authorization. H.R. 3444 does not require specification of purpose, and H.R. 2979 does not require specification of content. Both H.R. 3444 and S. 503 require that the authorization include an expiration date, and S. 503 adopts the one year maximum authorization suggested by the Commission. H.R. 2979 does not require that an expiration be included.

In sum, S. 503 provides the strongest protection that an individual will understand what disclosures are being authorized, for what purpose the information will be used, and for how long the authorization will be effective. S. 503 also most clearly parallels the authorization recommended by the Commission in its report.

III. UNAUTHORIZED DISCLOSURE (See generally S. 503 § 206; S.865/H.R. 3444 § 105(b); H.R. 2979 §§ 121-132)

The Privacy Commission severely limits the circumstances under which medical information can be disclosed to third parties without authorization. This approach follows logically from a recognition of an individual's fundamental right to control dissemination of personal medical information, as well as from the fact that a legitimate, enforceable expectation of confidentiality can only evolve in a context in which unauthorized disclosure is permitted by the Commission in only a few carefully defined situations.

Each of the bills incorporates the exceptions suggested by the Commission, but in many cases these exceptions are broadened substantially at the expense of the individual's privacy interest. In addition, each bill creates new categories wherein disclosure is permitted without prior authorization. Attention will first focus on the categories adopted by the Commission as modified by the bills, and then will turn to the additional categories included in the various bills. Obviously the effect of expanding upon the Commission's carefully defined categories, either by broadening the scope of a suggested category or by creating a new one, will be to erode the individual's expectation of confidentiality.

A. Exceptional Circumstances as Defined by the Privacy Commission Under Which Authorization for Disclosure Is Not Required:

1. To another medical care provider who is being consulted in connection with the record subject's treatment. (See S. 865/H.R. 3444 § 105(b)(2), H.R. 2979 § 122.)
2. Upon a showing of compelling circumstances affecting the health and safety of an individual. Adopted by each of the bills. (See S. 503 § 206(b)(7), S. 865 H.R. 3444 § 105(b)(4), H.R. 2979 § 126.)
3. For research purposes. The Commission would allow unauthorized disclosure of medical information for research purposes, but only within carefully defined limits. The three bills vary in the degree to which

protection is afforded the individual whose record may be used for research purposes. (See S. 503 §206(b)(9); H.R. 3444 § 105(b)(5); H.R. 2979 § 124.) S. 503 is deficient in that all that is required is approval by an institutional review board and by the service provider director or his designee before information can be disclosed to a researcher.

S. 865/H.R. 3444 and H.R. 2979 each have strengths and weaknesses and hopefully and final version will incorporate the positive elements of both. The issues involved Include:

a. Importance of the Project: Both S. 865/H.R. 3444 and H.R. 2979 require that a preliminary determination be made that the importance of the project outweighs the risk or intrusion that disclosure involves. H.R. 2979 requires that this determination be made by an Institutional Review Board (established by the Secretary pursuant to the Public Health Service Act); and S. 865/H.R. 3444 permits but does not seem to require the decision be made by an Institutional Review Board.

S. 503 requires approval by both an Institutional Review Board and the director of the service provider or his designee. However, the value of this dual approval requirement is undermined, because approval is not made conditional upon a finding that the importance of the project outweighs the risk involved in disclosure, as under the other bills.

In addition to approval by an Institutional Review Board, the ACLU recommends that disclosure of research purposes should also be authorized by the physician primarily responsible for the case of the patient. If the patient has been discharged, approval should be made by the chief of the particular medical service unit which cared for the patient. Approval by the attending physician or the unit chief will ensure that the disclosure is acceptable to the party most closely identified with the welfare of the particular patient. It will also counteract any tendency on the part of the Institutional Review Board to make inappropriate or intrusive disclosures that may result from its pro-research orientation. Both the Institutional Review Board and the attending physician or unit chief should conclude that the importance of the project outweighs the risks involved in disclosure, before granting approval.

b. Necessity of the Information: Only S.865/H.R. 3444 provides that the facility must condition disclosure upon a determination that the project cannot reasonably be conducted without the information. This requirement was also incorporated in the recommendation of the Commission.

c. Further Disclosure by the Researcher: The Commission recommends that no further disclosure of information in identifiable form be allowed by the researcher, absent the written consent of the dis-

closing facility. However, both S. 865/

H.R. 3444 and H.R. 2979 allow redisclosure by a research-recipient under the following circumstances:

- i. Both allow disclosure to employees or agents involved in the project to the extent necessary to carry it out.
- ii. Both allow redisclosure for the purpose of auditing or evaluating the project; S. 865/H.R. 3444 requires that the audit be authorized by statute or contractual agreement.
- iii. S.865/H.R. 3444 allows disclosure to meet a medical emergency or to prevent a crime which may involve personal injury; H.R. 2979 allows redisclosure if there are compelling circumstances affecting the health or safety of any person or involving imminent danger of property damage.
- iv. Both allow redisclosure for use in other health research projects, and each provides that such disclosure must be consistent with the other limitations on use of medical information in research projects (i.e. determination of importance, compliance with other safeguards, etc.).

[Note: It does not seem either appropriate or necessary to allow redisclosure by a research-recipient. Access to necessary information can be obtained from the original disclosing facility. This would be the most appropriate channel since HEW's power to sanction non-compliance (i.e. improper disclosure to a research project) rests largely in its ability to withdraw federal funds from health care facilities covered by the legislation. Not only is a researcher-recipient beyond the reach of

this central enforcement mechanism, it also is not the proper party to weigh the importance of a proposed second research project against the risk to the individual of the redisclosure. The original medical care provider will be more likely to properly consider the privacy interests of a past or present patient, than will an isolated research facility strongly committed to research and totally uninvolved in actual service delivery.]

d. Removal where possible of Identifying Information.

S. 503 properly places a prohibition on disclosure by researchers of a patient's identity in a research report or in any other manner (§ 206(g)). This provision minimizes the risk of inappropriate redisclosure. However, as discussed below, if the information is obtained by a government authority, for research or any other purpose, redisclosure to another agency is routinely permitted (see § 214; see also Section V of this report: Redisclosure).

Both H.R. 2979 and S. 865/H.R. 3444 place the research-recipient under an obligation to remove where practicable identifying information. S. 865/H.R. 3444 require that this be done at the earliest possible time.

e. Additional Safeguards. H.R. 2979 requires the Secretary to establish security standards to be followed by researchers, auditors and evaluators who are in possession of medical record information. These standards, along with a list of the other requirements will be furnished to each research-recipient.

S. 865/H.R. 3444 expressly provides that the facility must determine that disclosure does not violate any of the limitations that were placed upon the use or disclosure of the information at the time that it was obtained. (This precondition is not explicitly stated in H.R. 2979). S. 865/H.R. 3444 requires the research-recipient to make assurances that appropriate safeguards will be established to protect against unauthorized use or disclosure. This approach will not provide the protection against abuse that would be provided by a strong set of security standards issued by the Secretary under H.R. 2979. H.R. 2979 and S. 503 also explicitly state that no disclosure of any identifiable information will be made in any public report issued by the recipient. S. 865/H.R. 3444 requires only that the recipient make assurances that appropriate safeguards will be established against unauthorized use or disclosure of the information.

A final version of the research provisions of a medical record privacy bill should incorporate a determination of "sufficient importance" by both an Institutional Review Board as well as the attending physician; a determination of "necessity"; a prohibition on redisclosure; and a mandate for strong security regulations.

4. For audit and evaluation purposes. The Commission Report as well as all of the bills permit unauthorized disclosure for auditing and evaluation purposes. (See S. 503 § 206(b)(3); S. 865/H.R. 3444 § 105(b) 6, 7; H.R. 2979 § 125.

a. Redisclosure: S.503 most closely follows the Commission recommendation that redisclosure be prohibited. (Disclosure under S. 503 is allowed only if required by law.) S.865/H.R. 3444 and H.R. 2979 allow redisclosure to employees or persons carrying out the audit or for whom it is carried out. Both also allow redisclosure under compelling circumstances affecting the health and safety of individuals (or property--H.R. 2979). These grounds for redisclosure are objectionable for the same reasons as is redisclosure by a researcher recipient (see above).

b. Safeguards: Both S. 503 and H.R. 2979 mandate that auditors and evaluators comply with security regulations promulgated by the Secretary. S. 865/H.R. 3444 is deficient in that it requires only that the auditors or evaluators provide assurances that adequate safeguards will be developed. Only H.R. 2979 explicitly prohibits disclosure of identifiable information in any public report.

5. Pursuant to a statute that requires disclosure to a government authority. All of the bills adopt this exception; but none requires notice of the disclosure to the individual as recommended by the Commission. (See S. 503 § 206(b)(4), S. 265/H.R. 3444 § 105(b)(8); H.R. 2979 § 127.)

6. Disclosure of location and health status
information regarding a patient, so long as the patient
does not object. H.R. 2979 and S.865/H.R. 3444 allow
 such unauthorized disclosures to be made. S. 865/
 H.R. 3444 would also allow disclosure of this information
 even if the individual objects, if disclosure is to a
 government authority pursuant to a legitimate law enforce-
 ment inquiry. This provision is objectionable. No
 standards as to "legitimacy" are provided, nor is any
 opportunity given to the record-subject to challenge the
 legitimacy of the inquiry (see S.265/H.R. 3444 § 105(b)(10),
 H.R. 2979 § 123).

7. Pursuant to lawful judicial summons or subpoena.
 This has been adopted with substantial variation tending
 to increase the scope of unauthorized disclosure. (See
 section on Government Access, below). Suffice it to say for
 present purposes that under all three bills the government
 may obtain access to records through legal process in a wide
 range of circumstances. Because of procedures for allowing
 government agencies to delay notice to the individual dis-
 closure can often be made without an individual's knowledge.
 Under S. 503 and S. 865/H.R. 3444 a formal written request
 can be used to obtain access when summons or subpoena
 power does not exist, thereby dangerously expanding the
 scope of unauthorized government access. (See S. 503
 §206(b)(10), S. 865/H.R. 3444 § 105(b)(11-12), H.R. 2979
 § 131.)

8. Pursuant to a statute that requires the medical care provider to report specified items of information about the individual to a law enforcement authority, provided the individual is notified of each disclosure.

Aside from disclosure made pursuant to legal process or in the event of compelling circumstances affecting an individual's health or safety, the Commission would limit unauthorized disclosures made to law enforcement authorities to those required by existing statute. Only if unauthorized disclosures to law enforcement authorities are carefully limited, along these lines, can an expectation of privacy surrounding one's medical records survive. This expectation is seriously compromised, insofar as each of the three bills allows the government to obtain access without authorization and without using legal process under a wide range of circumstances.

a. H.R. 2979 allows such disclosure:

- i. to assist in the identification of a dead person (§ 126(a));
- ii. upon a showing of compelling circumstances involving imminent danger of serious property damage (§ 126(b));
- iii. for use in an investigation or prosecution (directed at any person other than the individual) of fraud, abuse, or waste in a program or project funded or operated by a government authority (§ 129(a)(1A));

- iv. to assist in the identification or location of a suspect or fugitive in a legitimate law enforcement inquiry (§ 129(a)(1B)).

Disclosures pursuant to (iii) and (iv) may be made so long as the government authority provides the facility with a written certification signed by a designated official of supervisory rank asserting that the record is being sought for a legitimate purpose within either (iii) or (iv). While the service provider must keep an accounting of any of these disclosures (i-iv), no notice is given the individual, and thus there is no opportunity for him to contest the relevance of the disclosure to the investigation, or for a judge to weigh the substantiality of the intrusion against the government's need for the information.

b. S. 865/H.R. 3444 allows government access without authorization for law enforcement purposes:

- i. if immediately needed to prevent imminent danger of serious property damage or flight to avoid prosecution (§ 105(b)(13);
- ii. if for a government public health investigation, or for a government investigation of activities of the facility (§ 105(b)(6A).
- iii. to conduct an investigation concerning fraud, abuse or waste under Title V, part B of Title XI, Title XVIII, or Title XIX of the Social Security Act (§ 105(b)(6B).

The government authority need only present a written statement at the time of disclosure (or shortly thereafter if under (i) above) of the need for the information. Within 5 days of gaining access under (i), the government authority must file a signed sworn statement with an appropriate court, setting forth the grounds for the emergency access.

c. S. 503 allows unauthorized disclosure for law enforcement purposes if:

i. the government authority determines that delay in obtaining access would create imminent danger of (a) physical injury to any person, (b) serious property damage, (c) flight to avoid prosecution (§ 211 (b)).

As under S. 865/H.R. 3444 (but not H.R. 2979) a statement justifying such emergency access must be filed in a court within 5 days. Notice must be given under S. 503, but since it is after the fact, no effective challenge exists. Notice may be delayed with the court's permission.

ii. the information is sought by a government authority in connection with lawful proceeding, investigation, examination or inspection directed at the service provider in possession of such information or at a legal entity which is not a patient or former patient. No notice need be given (§ 210 (d)(1)).

- iii. information regarding the individual's presence at the hospital, and his present condition, if sought pursuant to a legitimate law enforcement inquiry.

B. Additional Categories of Permissible Unauthorized Disclosures Incorporated by Bills

In addition to these expansive modifications in the categories recommended by the Commission, each of the bills also permits unauthorized disclosure under a variety of other circumstances. H.R. 2979 creates the fewest additions to the Commission list, while S. 865/H.R. 3444 expands it considerably, at the expense of the individual's privacy interest.

1. Under H.R. 2979 unauthorized disclosure is also permitted:

- a. for use by the Secret Service, or by authorities authorized to conduct foreign counter or positive intelligence activities, upon receipt of a certification as to the legitimacy of the request. The medical facility is prohibited from disclosing to anyone that access has been obtained for these purposes. Since an individual will never learn of such a disclosure, he/she will never have an opportunity to contest its legitimacy. Consequently, acquisitions by Secret Service and foreign intelligence agencies are effectively beyond the civil and criminal action enforcement mechanisms, to the extent that such actions are generally initiated by the aggrieved individual (see § 128). For further discussion of these exceptions see Government Access below.

b. pursuant to the Federal Rules of Civil or Criminal Procedure or comparable rules of other courts or administrative agencies in connection with litigation or proceedings to which the individual is a party (§ 130).

2. S. 503 makes the following additions to the list of unauthorized disclosures suggested by the Commission:

- a. For Secret Service and foreign intelligence purposes. Same incidents as under H.R. 2979 (§ 211(a)(1)).
- b. Pursuant to Rules of Civil or Criminal Procedure, as under H.R. 2979 (§ 210(b)).
- c. For information sought by the General Accounting Office pursuant to an authorized proceeding, investigation, examination or audit directed at a government authority.
- d. Pursuant to a formal written request by a government authority when it reasonably appears "that no administrative summons or subpoena is available" (see Government Access below) (§ 206(b) 10; § 209).
- e. To a parent, guardian, or legal custodian of a patient (i) less than 12 years of age or (ii) physically or mentally incompetent; if the service provider determines that disclosure is appropriate under the circumstances.
- f. To the immediate family or any other individual with whom the patient is known to have a close relationship, if the patient is incapable of giving authorization due to a bona fide medical emergency. (§ 206(b)(6)).

3. S. 865/H.R. 3444 makes the following additions to the list of unauthorized disclosures suggested by the Commission:
- a. For Secret Service and Foreign Intelligence purposes. Same incidents as under H.R. 2979 (§ 105(b)(16)).
 - b. Pursuant to Rules of Civil or Criminal Procedure as under H.R. 2979 (§ 105(b)(14)).
 - c. To the next of kin or persons with whom the individual has a personal relationship, consistent with accepted medical practice (§ 105(b)(3)).
 - d. To a government official, if to carry out a program under Title V, part B of Title XI, Title XVIII, or Title XIX of the Social Security Act, or other government program providing payments to, or concerned with activities of the facility (§ 105(b)(6B)).
 - e. To persons who state in writing that they need the information for the purpose of carrying out a program providing payments to the facility (§ 105(b)(7)).
 - f. For medical information pertaining to a member of the uniformed services in materials belonging to any of the uniformed services (§ 105(b)(17)).
 - g. For information in materials belonging to a penal or correctional authority (§ 105(b)(18)).
 - h. For information belonging to or in the custody of the Veterans Administration or its contractors or any of the uniformed services for the purpose of determining or providing benefits (§ 105(b)(21)).

i. To a government authority, or to a third party potentially liable or responsible to the medical care facility for the cost of providing services to an individual, for the purpose of processing a claim related to medical services received by an individual (§ 105(b)(22)).

j. Pursuant to a formal written request (§§ 105(b)(11), 206).

k. To a person other than a government authority pursuant to compulsory legal process (§ 105(b)(20)).

The purpose of requiring an authorization by a record-subject as a pre-condition to disclosure is to promote and protect the individual's legitimate expectation of confidentiality regarding personal medical records. To the extent that the authorization requirement is riddled with exceptions, this purpose is necessarily frustrated, and the expectation of confidentiality is undermined. Many of the additional exceptions incorporated in the bills create unwarranted intrusions on the individual's right to control disclosure. Where the need for the information is not immediate, there is no reason not to seek authorization by the record subject. The third party seeking disclosure should, if it is a government agency, be forced to resort to legal process to obtain the information should the individual refuse to disclose.

IV. GOVERNMENT ACCESS

Any limits placed on the discretion of health care providers to disclose medical information voluntarily will be ineffective in promoting a legitimate expectation of privacy if the government still retains an unlimited right of access to these records through informal requests or compulsory process which cannot be contested by the record subject. Consequently, the recommendations presented by the Privacy Commission are premised on the notion that medical records should not be accessible to government unless a compelling governmental interest outweighing the individual's interest to be free from government intrusion can be shown. In order to protect the privacy of the individual, as well as to encourage government agencies to limit themselves to legitimate information requests, the Commission recommended that requests for medical records be made only through recognized legal process unless it is with the consent of the record subject. An individual who is given prompt notice of an agency's invocation of legal process to secure his record will have an opportunity to challenge the propriety of a disclosure before it occurs. Only when there is "reasonable cause" to believe that the record is relevant to a legitimate investigation, and the government can show that its law enforcement needs in the particular case outweigh the individual's presumptive right of privacy, should the request be made and granted.

All of the bills deviate from these principles to varying degrees. Each of the bills allows government access to medical records without requiring use of legal process, in a wide range of circumstances.

A. Government Access Can Be Obtained Without Legal Process

1. Under H.R. 2729:

a. Pursuant to a showing of compelling circumstances affecting the health and safety of any person or involving imminent danger of serious property damage (§ 126);

b. By the Secret Service or a government authority authorized to conduct foreign counter or positive intelligence activities. The government agency is obligated only to provide a certification signed by an officer of supervisory rank that the record is sought for a "legitimate" secret service or foreign intelligence purpose (§ 128).

Note: The blanket exceptions to both the authorization and legal process requirements made for the Secret Service and foreign intelligence agencies are seriously destructive of an individual's privacy interest. Under each of the bills, these agencies would have virtually unfettered access to medical record information. Disclosure is authorized as long as the requesting agency asserts that the inquiry is legitimate. Absolutely no protection is offered the record subject against inappropriate or unnecessary disclosures made to a well intentioned but misinformed or over-zealous investigator.

There is no justification for wholesale access to medical record information granted by these bills. Presently the Secret Service is given only limited access to medical record information in some states, and in Massachusetts access is uniformly denied. The fact that the Secret Service has functioned adequately in these states indicates that the blanket exception offered the agency in the proposed bills is unnecessary. Given the agency's ability to adapt to the laws in Massachusetts and elsewhere, the Secret Service should be required to resort to the same channels as other govern-

ment agencies (i.e., legal process) in order to gain access to confidential information. The suspension of notice provisions (see below) are adequate to protect the investigation.

Along these same lines, the needs of the agencies carrying out foreign intelligence activities should not run roughshod over the privacy interests of a record subject. An appropriate balance between the needs of the government and protection of the individual is reflected in the Foreign Intelligence Surveillance Act of 1978. Access to an individual's medical records should be allowed for foreign intelligence purposes only in those situations wherein a foreign security wiretap would be permitted. Applying the standards of the Surveillance Act, access to records would be conditioned on the approval of the Attorney General on the basis of a written finding that there is probable cause to believe that the person whose records are sought is an agent of a foreign power as defined in Sec. 101(b) of the Foreign Intelligence Surveillance Act of 1978.

Elimination of the exception for the Secret Service and modifying procedures for access by the foreign intelligence community will protect the individual's expectation of privacy without unreasonably interfering with the operations of the affected agencies.

- c. (i) For use in any investigation (not directed at the individual) of fraud, abuse or waste in a program funded or operated by the government, or
- (ii) To assist in the identification or location of a suspect or fugitive in a legitimate law enforcement inquiry. All that is required in either case is a signed certificate that the information is sought for a legitimate purpose under the section (§ 129).
- d. Pursuant to the Federal Rules or comparable rules of other courts or administrative agencies in connection with proceedings to which the individual is a party (§ 130).

Mr. PREYER. Our final two witnesses today are two representatives of the Treasury Department, Under Secretary Ms. Bette B. Anderson and Director of the U.S. Secret Service, H. Stuart Knight.

I understand, Ms. Anderson, that you are a last-minute replacement and we appreciate your coming on such short notice. If you have any written opening statements, we will make them a part of the record and you may read it or summarize it or proceed in any way you choose.

STATEMENT OF BETTE B. ANDERSON, UNDER SECRETARY, DEPARTMENT OF THE TREASURY; ACCOMPANIED BY H. STUART KNIGHT, DIRECTOR, SECRET SERVICE

Ms. ANDERSON. Thank you, Mr. Chairman, for the invitation to testify here today on your proposed medical privacy legislation. Accompanying me, as you stated, is Mr. H. Stuart Knight who is the Director of the Secret Service.

We endorse this legislation, particularly the disclosure exception for the U.S. Secret Service. We intend to focus our discussion on this exception as is provided in section 128 of your draft bill and why we feel such an exception is necessary for the Secret Service in order to carry out its protective function.

The administration has also submitted a medical privacy bill which contains a similar exception for the Secret Service and we support the administration's position.

I would like to state that I would like to give my statement complete and that the Director will briefly summarize his and handle the questions and save time.

This is not a subject which the Department takes lightly. Individual right to privacy is a concept for which we personally have the highest respect.

Mr. KOSTMAYER. Mr. Chairman, how long do you think it is going to take to read the whole thing? We have so little time. I have to go to another meeting. Is it possible for you to summarize?

Ms. ANDERSON. I would prefer not to because I think every single point that is made in here has been alluded to this morning by previous witnesses. I will do it just as rapidly as I can.

Mr. KOSTMAYER. Thank you very much.

Ms. ANDERSON. Medical records in particular often contain the most sensitive information about an individual. It is the kind of information which should have the highest possible level of protection and confidentiality. We endorse your bill in principle because it achieves just that.

Notwithstanding our views on the need for privacy of medical records, it is also our opinion that an outright exception to the prohibition to disclosure of medical records is absolutely necessary for the U.S. Secret Service.

By the nature of its mission, the Secret Service must deal in terms of prevention. One of the many preventive measures taken by the Service is to maintain contact with mental institutions to remind them of the Service's existence and our interest in information which may reveal that an individual may pose a threat to a Secret Service protectee.

It is not our intention to infringe on the individual's rights to privacy. However, it is necessary to balance an individual's right to the privacy of his medical records with legitimate needs of the Secret Service for access to this type of information which under certain specific and limited circumstances is necessary in protecting the life of the President and other protectees. Section 128 of your bill would adequately deal with the Secret Service's need for this information.

I would like to take a few minutes now to address the reasons why Secret Service access to this type of personal information is so necessary to effectively carry out our protective mission.

First, I would like to present some background information on the origin and legal basis for our use of certain medical information in investigations connected with our protective functions.

Following the 1950 attack on President Harry S Truman, Congress enacted title 18, United States Code, section 3056, which gave the Secret Service complete statutory authority to protect the President, his immediate family, the President-elect and the Vice President.

Congress has since expanded this authority to include the protection of additional protectees such as the Vice President-elect, a former President and his wife, and visiting foreign heads of state.

After the assassination of President John Kennedy in 1963, the Warren Commission reported its findings and recommended an enlarged and more sophisticated protective operation for the Secret Service. The Warren Commission emphasized that the Secret Service should not limit its interest to persons communicating actual threats to the President, and stressed the importance of advance detection of potential threats against the President.

The Commission also indicated that to require some manifestation of hostility against a Government official was unduly restrictive as a criterion for furnishing information.

Accordingly, the Commission recommended that the Secret Service broaden and formalize liaison with other agencies to obtain preventive intelligence. Based on this recommendation, Secret Service field offices were specifically directed to give greater emphasis to liaison with Federal, State, and local law enforcement agencies, institutions for the mentally ill, and other potential sources of protective information. This was the origin of our present procedure.

In accomplishing this liaison, the Secret Service solicits from mental health institutions the voluntary identification of persons in their care who are characterized by any of the following categories: (1) Has expressed an unusual interest in any protectee or category of protectees, which in the opinion of the facility or health professional, could present problems affecting the safety of individuals within the protective jurisdiction of the Secret Service; (2) has threatened or assaulted local, State, or Federal Government officials, excluding law enforcement officers; or (3) may present, in the opinion of the facility or health professional, a possible danger to individuals within the protective jurisdiction of the Secret Service.

In addition, the Secret Service may, on occasion, seek information from a mental health institution on an individual who has

already been identified by the Secret Service as being of continuing protective interest.

It is common belief that only those agents seen in close proximity to a protectee are effecting his or her protection. This is far from true. Protection involves concerted efforts in long-range advance planning and preparation.

A basic element of protection is the early identification of possible sources of danger. The present Secret Service policy of maintaining liaison with mental health institutions is an operational application of this principle.

The Secret Service is interested in obtaining medical history information because historically the Service has found that the majority of persons who threaten and/or exhibit unusual interest in our protectees suffer from some form of mental illness.

A review of Secret Service files indicates that at least 75 percent of the individuals of record with this Service who have threatened and/or expressed an unusual interest in official persons and their families or installations of interest to this Service have a known history of mental problems.

Moreover, more than 90 percent of the individuals considered dangerous to protectees of this Service have a known history of mental problems. Thirty-three percent of these individuals considered dangerous are currently institutionalized in mental health facilities.

That statistical evidence explains the continuing interest of the Secret Service in individuals with mental problems. These individuals comprise the bulk of those subjects of serious protective interest to the Service.

The Secret Service depends on the expertise of the psychiatrist or hospital staff as to which individuals they feel they can or should bring to our attention. The categories described above merely provide guidance to the health professionals in recognizing which persons may be of interest to the Service.

Liaison with medical care facilities which treat the mentally disturbed is an essential means of identifying those individuals who, in the opinion of an institution's doctors or officials, may be of protective interest to the Secret Service.

Information concerning an individual's mental health condition is acquired in two fundamental situations: One is through voluntary identification by a physician of institution as a result of routine liaison; the other is in response to a specific inquiry by the Secret Service where a particular individual has been identified as a possible threat to a protectee.

Each special agent in charge of a field office has the responsibility for insuring that the proper officials in all hospitals and institutions treating the mentally ill understand the Service's interest.

The Service is dependent on the institution's doctors and officials for bringing possibly dangerous persons to its attention. It usually relies on their professional opinion in making this determination. The Service is only looking for information to assist it in determining the degree of danger an individual presents to a protectee.

In most cases, it is not necessary or even desirable to review a file if a doctor, hospital administrator, and so forth will give a

general idea of the individual's problem and an evaluation of his propensity for violence against a protectee.

The Secret Service is of the opinion that the procedure of maintaining liaison with hospitals and institutions for the mentally ill is vitally important to the overall preventive intelligence effort.

Based on the statistical data previously cited, the Secret Service would be remiss if it did not concern itself with the potential threat to the President presented by this class of individuals. Secret Service efforts in this area are in accordance with the recommendations of the National Advisory Committee on Criminal Justice Standards and Goals.

In 1976, this committee published a lengthy study, titled "Disorders and Terrorism," from which the following is quoted:

What, then, are the duties of the psychiatrist whose patient's fantasies of quasi-terroristic mass murder appear practical and possibly realizable? Or, to pose another example, what are the duties of the attorney to whom politically motivated terrorist clients divulge plans of future bombings?

The recommendations contained in this standard are far from being revolutionary in their content; general duties of confidentiality notwithstanding, codes of professional ethics recognize that under some circumstances, members of the helping professions are not only permitted but also obliged to notify law enforcement authorities of impending dangerous acts by clients, patients, and others. In some jurisdictions, special duties to report impending acts of violence that override the general duty to observe confidentiality have actually been imposed by legislation or judicial action.

As indicated in the above excerpt, on occasion, it is necessary to disclose information which may be considered confidential by a patient and his psychiatrist in order to prevent the occurrence of an act of violence. This type of notification is especially important where the Secret Service protective function is concerned.

We recognize that when we receive this information it is for a very limited purpose. Therefore, all protective intelligence information received by the Secret Service is handled with the utmost discretion to protect the privacy of the individuals concerned. In particular, all information received as a result of Secret Service liaison with mental institutions is handled with strictest confidence.

Protective intelligence files of the Secret Service are maintained and used by the Service only in its protective function. This is the only use of these files. They are not mingled with other files such as ordinary criminal histories.

There is no access to these files by any other agency for criminal investigating or other purposes. They are not part of any multi-agency computer system and cannot be queried by either the National Crime Information Center—NCIC—of the FBI or Treasury's own Treasury Enforcement Communications System—TECS.

Within the Secret Service itself, access is strictly controlled by personnel of the Intelligence Division of the Office of Protective Research.

These tight restrictions apply equally to the input of data into the files of the Secret Service. Input, like retrieval, is within the exclusive domain of the Protective Intelligence Division of the Secret Service.

Only in certain life-threatening situations may intelligence information be disclosed to another law enforcement or governmental

agency if it is felt that it may be of assistance. A situation of this type occurred on March 9, 1977, when 12 members of the Hanafi Muslim sect armed with automatic weapons, machetes, and small arms took over the B'nai B'rith Building, the Islamic Center, and the District Office Building in Washington, D.C., and held 134 hostages.

The siege lasted for 39 hours and resulted in the death of one person and several injuries. During the siege, it was determined that one of the perpetrators was of prior record with this Service. Information regarding this individual was released to another law enforcement agency to assist in the negotiations.

Again, the unconsented to disclosure of this information to other law enforcement representatives by this Service is infrequent and occurs only when it is felt that it would be of assistance in a life-threatening situation. This type of disclosure is permitted by the Privacy Act of 1974.

I appreciate this opportunity to comment. Director Knight will not discuss the basic procedures which the Secret Service follows in obtaining medical information.

Mr. KNIGHT. Thank you.

I do have a statement, but I will submit that for the record.
[Mr. Knight's prepared statement follows:]

FOR RELEASE ON DELIVERY

June 14, 1979

STATEMENT OF THE HONORABLE H. STUART KNIGHT
 DIRECTOR OF THE UNITED STATES
 SECRET SERVICE BEFORE THE
 SUBCOMMITTEE ON GOVERNMENT INFORMATION AND INDIVIDUAL
 RIGHTS COMMITTEE ON GOVERNMENT OPERATIONS
 HOUSE OF REPRESENTATIVES

H. R. 2979
 Privacy of Medical Records

After reviewing H. R. 2979, specifically Section 128
 (1) (A), the Secret Service strongly supports this
 section as written.

I share Assistant Secretary Davis' and this committee's
 concern over an individual's right to privacy. The
 Secret Service has always exhibited particular care in
 safeguarding the sensitive knowledge which it must
 acquire in order to carry out its protective responsi-
 bilities.

As Mr. Davis has outlined, the historical emphasis on
 preventive intelligence places on the Secret Service
 a clear obligation to continue to investigate all
 possible sources of danger to our protectees. Statistical
 evidence has supported this need.

There are two fundamental situations in which the Secret
 Service acquires information concerning an individual's
 mental condition. The first is through voluntary
 identification by a physician or institution as the
 result of routine liaison. The second is in response
 to an inquiry on a specific and previously identified
 individual.

In the first situation, it is essential that the Secret
 Service be advised of any individuals who are presently
 in hospitals, mental institutions, or under a doctor's
 care, who have made threats against the President or
 other protectee and the Service is not aware of such
 individuals.

Each Special Agent in Charge of a field office has the
 responsibility of establishing liaison with hospitals
 and institutions treating the mentally ill. The purpose
 of this is to ensure that the proper officials in those
 institutions understand this Service's interest in
 identifying individuals who may threaten the President.

The Secret Service is dependent on the institution's
 doctors and officials for bringing these potentially
 dangerous persons to our attention. Without this
 voluntary cooperation, many of the persons who may be
 dangerous to the President would not come to our atten-
 tion until they have committed a violent act.

Secondly, the Secret Service also has need for medical information regarding individuals who have already threatened the President. In these cases an investigation is already underway to determine the degree of danger the individual presents.

The Secret Service is made aware of individuals who have threatened a protectee through a variety of ways. These include letters and telephone calls to the White House, private citizens and police officers reporting conversations or statements made by an individual, etc. The Secret Service is obligated to investigate each and every such occurrence.

It has been historically shown that in conducting such an investigation the most important factor is the personal interview of the individual by the investigating agent. Second to the personal interview, is to know whether or not the individual has a record of mental illness or disorder.

It should be evident that in the difficult task of predicting human behavior, and in particular predicting dangerousness, some insight into a person's mental illness or disorder is of invaluable assistance. Evaluation by a medical doctor is also essential in making this determination.

It is Secret Service policy to first obtain the individual's written permission to seek information concerning his mental record. We are looking for information that would assist us in determining the degree of danger the individual presents to a protectee. In most cases it is not necessary to even review a physical file if a doctor, hospital administrator, etc. will give us a general idea of the individual's problem. Of greater importance is an evaluation of his propensity for violence and dangerousness. The Secret Service limits its interest in medical information to only the identity of and the professional evaluations concerning the individual.

Due to the above two needs, legislation that would authorize the Service to obtain necessary medical information would most certainly impact favorably on the Service's protective mission.

At the present time, almost every state has a mental health code that restricts the access to medical records and release of information about the medical history of a patient. Some states have a more restrictive mental health code than others but, generally speaking, all state mental health codes cause the Secret Service problems to some degree.

As a general rule, most mental health codes have methods by which information may be obtained about a mental patient's record. The methods are by written permission of the patient or by court order. These two means are satisfactory to most agencies seeking information such as a prosecutive investigation or background investigation. In these cases time is not the problem and making a behavioral prediction is not the purpose.

Although the Service tries to get the written permission of an individual to review his or her medical records, it is not always possible. In many cases the subject does not want his mental history known since it would reflect on the words or action that brought the individual to our attention.

In some cases, written permission is out of the question because the subject is being sought by this Service and his whereabouts are unknown. In these cases the person's mental condition, propensity for violence and possible behavior when located would be invaluable information to the agents who approach the individual.

In many situations the subject under investigation has not broken any law and therefore a court order is not possible. An example is where an individual writes to the President and the letter contains a veiled threat or extremely abusive language. If it is learned that the subject has a mental history, it would be important to obtain an evaluation with or without permission. Since no law has been broken a court order cannot be obtained.

In almost all cases it is imperative for this Service to make a determination of whether or not an individual presents a danger to a protectee as quickly as possible. Time, then, is a critical factor in the investigation. The Service therefore needs access to medical information on a timely basis. This evaluation is the singular reason, and use, for collecting medical information.

The mission of the Secret Service is to prevent an assassination before it occurs. The status of persons potentially dangerous to the President must be determined as quickly as possible. In these cases there is not time to obtain a court order.

Statistical review of Secret Service cases has found that the majority of persons who threaten our protectees suffer from some form of mental illness. The statistics

included in Mr. Davis' statement certainly justify our continued interest in the mentally ill person. In all cases we depend on the expertise of the doctors as to which individuals they feel should be brought to our attention.

Intelligence files are maintained at our headquarters in Washington, D.C., which is manned 24 hours a day. Those files that have remained inactive for five (5) years are destroyed. Judicial cases and selected high priority cases are destroyed after twenty (20) years.

Very few Intelligence files are kept by the field offices. They are instructed at the close of a case to make certain headquarters has the complete original file.

All medical information received by the Secret Service is always handled with the utmost discretion to protect sources and the privacy of the individuals concerned.

Section 128 of this bill exempts us from restrictions placed on access to medical records. It does so by permitting access to records in connection with the performance of our protective functions.

However, it should be noted that section 102(b)(3) states that this bill does not preempt existing Federal, State or local laws regarding access to psychiatric, psychological or mental health treatment records. These are precisely the records that we need and seek to accomplish our protective intelligence investigations.

Therefore, even though we have the exemption granted us by Section 128, other Federal, State or local laws would still control our access to psychiatric information.

In summary, our ability to evaluate protective intelligence situations is closely linked to our ability to obtain timely and accurate medical information. The provisions of H.R. 2679, Section 128 (1) (A), would allow the Secret Service to receive medical information, as needed, and thereby assist in fulfilling our protective responsibilities.

Mr. KNIGHT. I wish to say in introduction that I am pleased to be here because I think with the exchange of information and views, that we have, that hopefully I can make the points that we feel need to be made so that you can consider them in your deliberations later on.

Mr. PREYER. Thank you very much.

Let me just make one point to clarify the discussion. I would like to point out that H.R. 2979, our bill, does not require hospitals to disclose medical information to the Secret Service. Hospitals under that bill will remain free to deny access when they think it is appropriate.

Mr. Kostmayer, you indicated you had to leave?

Mr. KOSTMAYER. I do. I have a luncheon at 12:30. Thank you.

Can you tell me how many hospitals the Secret Service has liaisons with?

Mr. KNIGHT. With regard to mental institutions, our internal operating procedures require that we have liaisons with all of them.

Mr. KOSTMAYER. How does that work? Do you have a fellow that calls in every week?

Mr. KNIGHT. Only when necessary, to remind the staff of our existence and our needs.

Mr. KOSTMAYER. What kind of conversation takes place between your liaison officer and the hospital?

Mr. KNIGHT. I presume that they have developed a good relationship and they perhaps stop by, have a cup of coffee and leave.

Mr. KOSTMAYER. In addition, do doctors call you from time to time to advise you that they have a patient that they feel may be posing a danger to a protectee?

Mr. KNIGHT. From time to time that occurs; yes.

Mr. KOSTMAYER. How often does that happen, every year?

Mr. KNIGHT. I am not sure I can answer that, Mr. Congressman. I can say it does happen. But how many times, I really could not say.

Mr. KOSTMAYER. Can you give me a ballpark figure?

Mr. KNIGHT. I cannot.

Mr. KOSTMAYER. Well, is it frequently or rarely? Is it 10 times, or is it 5,000 or 10,000 times?

Mr. KNIGHT. Perhaps this will happen. We would open in the span of a year, less than 4,000 investigations involving individuals whom we feel pose a threat to the safety of the people we protect.

Mr. KOSTMAYER. When you use that figure 4,000, you are not just talking about mental patients. You are talking about everyone?

Mr. KNIGHT. No, but I am leading into the mental aspect.

Mr. KOSTMAYER. But those 4,000 are not necessarily mental patients?

Mr. KNIGHT. Predominantly, though.

Mr. KOSTMAYER. Predominantly?

Mr. KNIGHT. Predominantly.

Mr. KOSTMAYER. Go ahead. Thank you.

Mr. KNIGHT. That might result in as many as 10,000 specific inquiries at mental institutions because within that 4,000 persons, they may have been hospitalized many times, as many as 15 times or in 15 different times.

Mr. KOSTMAYER. So you say 15,000 inquiries. You do not mean 15,000 people?

Mr. KNIGHT. No, 4,000 people who would result in 15,000 inquiries.

Mr. KOSTMAYER. Now, what happens to these 4,000 names?

Mr. KNIGHT. There is a resolution made as to whether or not, first of all, he or she is in fact, a danger to the President, or to anyone we protect. If they are not in our best judgment and that is a judgment call, the case is closed.

Mr. KOSTMAYER. And what happens to the name then?

Mr. KNIGHT. The name stays in our files for 5 years.

Mr. KOSTMAYER. Five years?

Mr. KNIGHT. Yes, sir. Then, it is purged completely.

Mr. KOSTMAYER. Why does it stay there for 5 years if it poses no danger whatsoever?

Mr. KNIGHT. If you recall, I said that is a judgment call and that is a backup to our judgment.

Mr. KOSTMAYER. Judgment as to whether or not the person was a danger to the President, not as to whether or not the name should be maintained?

Mr. KNIGHT. No. A judgment call as to whether or not this person is a danger to someone we protect. We feel as a backup to that, we ought to just keep it for 5 years in the event—

Mr. KOSTMAYER. If it is a danger?

Mr. KNIGHT. No, if it is not a danger.

Mr. KOSTMAYER. I understand why you want to keep the names of people who you feel pose a danger. I do not understand why you are keeping the names of people who you feel—and it is a judgment call and I agree with you—do not pose a danger.

Mr. KNIGHT. At that point and at that time. We would like to have 5 years in the event—we conduct no additional investigation—but, in the event they come to our attention again, we could go back and evaluate that again.

These people do come up from time to time.

Mr. KOSTMAYER. These nondangerous people?

Mr. KNIGHT. That is right.

Mr. KOSTMAYER. So you have got all these names now on file, and the protectee goes into a city where one of these dangerous or nondangerous people lives or works. What do you do now?

Mr. KNIGHT. Well—

Mr. KOSTMAYER. Especially in terms of your relationship with the local law enforcement people.

Mr. KNIGHT. Those that we consider a danger, we would establish two things.

Mr. KOSTMAYER. Again, we are dealing only with the people who you have decided might be a danger.

Mr. KNIGHT. Correct.

Mr. KOSTMAYER. Right.

Mr. KNIGHT. Establish two things. No. 1, present whereabouts and No. 2, if we can—and this is very difficult—present state of mind or attitude vis-a-vis what they might do to the President or anyone else.

Mr. KOSTMAYER. How do you establish their whereabouts?

Mr. KNIGHT. Well, we can check his home address—we may very well know where he lives or works in order to confirm his whereabouts.

Mr. KOSTMAYER. You send an agent or you call him up?

Mr. KNIGHT. Send an agent in most cases, however telephone calls are sometimes used.

Mr. KOSTMAYER. It is straightforward. You get help from the local police?

Mr. KNIGHT. Yes, sir.

Mr. KOSTMAYER. That means you have got to give this individual's name to the local police?

Mr. KNIGHT. Right.

Mr. KOSTMAYER. That seems to be a contradiction. I thought you don't share this information.

Mr. KNIGHT. No, we do not share the information as to why we want it. We may run a criminal records checks to see if he or she has been arrested since the last visit. But, we would do that ourselves.

Mr. KOSTMAYER. You can give the name of this person to the local police?

Mr. KNIGHT. To run a criminal records check.

Mr. KOSTMAYER. But, you also told us you did not share this information with the local authorities.

Mr. KNIGHT. But, if I give your name to the local police department to run a criminal records check for me, I don't have to tell the local police department why I want it.

Mr. KOSTMAYER. We are referring to the fact of the matter. You are giving this individual's name who has broken no law to the local police department and at the same time, the local police have been given this information?

Mr. KNIGHT. I am asking the police if they have a criminal record on individual "A." We do this time and time again in connection with our criminal investigations.

Mr. KOSTMAYER. You don't have any conversation with the local police about this individual at all?

Mr. KNIGHT. At the same time we would be running a record check on a number of people for criminal cases that we are working on.

Mr. KOSTMAYER. So, you try and establish the whereabouts of the individual?

Mr. KNIGHT. Correct.

Mr. KOSTMAYER. If you are not able to establish the specific whereabouts in that particular city, what do you do then? You have a feeling the individual is in the city, but you cannot locate his domicile, what do you do?

Mr. KNIGHT. If we can't locate him, then we can't.

Mr. KOSTMAYER. Do you persist?

Mr. KNIGHT. Certainly.

Mr. KOSTMAYER. How do you determine state of mind?

Mr. KNIGHT. We will go to his psychiatrist and say has he changed? What is his propensity for violence? Make an assessment. Give us your best advice.

Mr. KOSTMAYER. How does the psychiatrist, if you can generalize here, how do the psychiatrists react to these visits from the Secret Service agents?

Mr. KNIGHT. I think they are well received.

Mr. KOSTMAYER. Thank you.

Thank you, Mr. Chairman.

Mr. PREYER. Mr. Butler?

Mr. BUTLER. Thank you, Mr. Chairman.

I appreciate the testimony of the witnesses. I would like to direct my questions to the area of the cooperation you are presently receiving from the medical profession and the hospital profession and what impact if any you think this legislation would have.

Certainly, section 128 says a medical care facility may disclose. That is implicit in the whole legislation.

Mr. KNIGHT. It is permissive. Also in section 102, I think, section (3) of 102, could be interpreted as excluding us from psychiatric or health records or mental health records. Of course, that is really what we are interested in. I have some concern about that that I would be happy to discuss with you or the staff.

Mr. BUTLER. You want us to clean that up a little bit?

Mr. KNIGHT. That is really what we are interested in. It is not whether or not the individual has a hernia in terms of the broad medical record.

Mr. BUTLER. It could drive you mad.

Mr. KNIGHT. You asked a question as to the cooperation and I guess that varies on a case-by-case basis. There are 50 different State laws. Texas and Massachusetts have basically the same law. But, they are interpreted and administered quite differently.

In Texas, we think within the bounds of their best judgment, it is quite cooperative. In Massachusetts, we don't get anything. So, it runs the gamut.

Mr. BUTLER. Well, with all due respect to the Representative from Massachusetts, I can understand the problem. If they started giving you the name of everybody in trouble, it would be a pretty overwhelming job.

But, in the sense that you are at the mercy under this legislation and at present of the judgment of the involved institution or physician, are you satisfied that, given the protection of this legislation, that the information you would need would still be forthcoming or do you need some stronger right to insist on this particular matter?

Mr. KNIGHT. As you and the chairman pointed out, this is permissive. We would like to see it mandatory. We would like to define why we need it, what we want and what we are going to use it for. That is a very narrow focus.

Permissive is subject to the vagaries of interpretation. We feel it would be better if it was obliged to be given to us.

Mr. BUTLER. Well, I would feel pretty good about that if you had all the safeguards that seem to be in the legislation about passing it on one way or another, implicitly as Mr. Kostmayer was suggesting.

But, let's assume that you are getting information that you need. What internal mechanisms do you have not to protect against its further dissemination?

Mr. KNIGHT. Not only are there mechanisms to prohibit disclosure outside of the Secret Service, there are also mechanisms internally to establish a need to know that information before anyone can have access to it who is already a member of my organization.

As Mrs. Anderson indicated, the files are kept totally apart and separate. Access to that is limited to few people. The demonstration must be of a need to know that information before it is even released internally, let alone externally.

Mr. BUTLER. What are the sanctions for violation of your procedures? If you find a particular employee or agent or whatever, if a particular employee has violated these internal safeguards, what do you do about that?

Mr. KNIGHT. First of all, I should say we have not had a case of violation. But, for my purposes, violation of this could lead to dismissal. There are no criminal sanctions because we do not have that authority. That would be the highest sanction we could use.

Mr. BUTLER. There is no question in your mind that you have, under existing legislation, employee protection and so forth, that if these internal sanctions are violated—internal guidelines are violated, that you could discharge an employee?

Mr. KNIGHT. I feel quite strongly about that. Some Federal district court would have to tell me differently. In other words, we put it at such a degree of sanctity that I think it merits that type of sanction.

Mr. BUTLER. I thank you, Mr. Chairman.

Mr. PREYER. Thank you.

Mr. Drinan, do you still have that question? [Laughter.]

Mr. DRINAN. Mr. Chairman, it has been refined.

Mr. Knight, we realize the very impossible job that you have, but I guess our role in this is to protect the privacy of people, even in the difficult circumstances when you feel that you need to know more about them.

And, in the bill as proposed, there is a prohibition for hospitals or agents from disclosing to any person that the Secret Service has sought and obtained access to their medical records.

Is that provision really necessary?

Mr. KNIGHT. Yes, I think it is, Mr. Congressman. There are a couple of reasons for that. One, I think that doctors in institutions would feel more comfortable giving that information to us if they knew that the patient was not going to be informed.

Second, in investigating a threat or even a plot to assassinate one of the people we protect, if they were immediately notified that we were inquiring about them, two things might happen—

Mr. DRINAN. I am not saying immediately. I am saying at 30 or 60 days when this thing does not check out, or the person is now released, under the basic law of privacy, we say that a person has a right to know if a Government agency has the information about their health, especially their mental health. Isn't it rational to say that after a designated period of time, they should know?

Mr. KNIGHT. When you put an element of time, it becomes more palatable to me. The only discussion then is how much time.

Mr. DRINAN. Couldn't it work to the benefit of the Secret Service? If this individual knew that the threats he made against the

President or the Vice President were in fact known to the Secret Service, wouldn't that be something of a deterrent?

Mr. KNIGHT. Not necessarily. He may figure that because we are investigating, he better move right away or flee, and then we would never know.

Mr. DRINAN. As you mentioned, there are a number of States that have severe restrictions and in your statement that you submitted for the record, you indicated generally speaking, all mental health codes cause the Secret Service problems to some degree.

In Massachusetts apparently you get no information. What results? Do you advise the President not to go to those States?

Mr. KNIGHT. Never.

Mr. DRINAN. We have to judge here as legislators how essential that information is.

Mr. KNIGHT. Yes, sir, you do.

Mr. DRINAN. We do. Give us some help. If you say—suppose half of the States refuse to give you information.

Mr. KNIGHT. I think No. 1, it would take us a great deal longer and time is often an important element in these matters. It would take us a great deal longer to reach a decision based on lack of information or less than the information we would like to have.

Our decisions may not have the validity that they should have.

Mr. DRINAN. Do you have any guidelines for informing the mental institution of your need?

Mr. KNIGHT. Yes, sir.

Mr. DRINAN. Are they printed? Could we get a copy of those guidelines?

Mr. KNIGHT. I think we could do that. As Mrs. Anderson indicated, we have liaison with the mental institutions.

Mr. DRINAN. I know, but it all sounded very informal. You call up your favorite shrink and say, what should we know? Are there guidelines spelled out?

Mr. KNIGHT. Yes, sir. There are guidelines. We can furnish you a copy.

Mr. DRINAN. I appreciate that. You wouldn't have them with you?

Mr. KNIGHT. No, sir, I do not.

[The material referred to follows:]

DEPARTMENT OF THE TREASURY
UNITED STATES SECRET SERVICE

WASHINGTON, D.C. 20223

DIRECTOR

June 28, 1979

Government Information and Individual
Rights Committee
Subcommittee of the Committee on Government
Operations
Room B-349-B-C
Rayburn House Office Building
Washington, D. C. 20515

Dear Mr. Chairman:

On June 14, 1979, Under Secretary Bette Anderson, Department of the Treasury, and Director H. Stuart Knight, U. S. Secret Service, testified before your committee.

At that hearing you requested a copy of the guidelines utilized by Secret Service field offices when contacting hospitals and mental institutions.

In response to that request the following excerpt from the Secret Service manual dealing with this subject is provided for your use:

Liaison with Hospitals and Institutions Treating the
Mentally Ill

Proper liaison must be maintained with all hospitals and institutions treating the mentally ill in each District. No record need be kept of visits to hospitals and institutions. However, it is the responsibility of each SAIC to ensure proper officials in all hospitals and institutions treating the mentally ill understand this Service's interest in identifying persons who are characterized by any of the following categories:

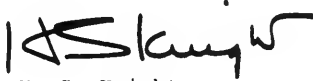
- (1) Has expressed an unusual interest which, in your opinion, could present problems affecting the safety of individuals within our protective jurisdiction.
- (2) Has threatened or assaulted local, state, or federal government officials, excluding law enforcement officers.



- (3) Any individual who, in your opinion, may present a possible danger to individuals within our protective jurisdiction.

Your request for copies of the State regulations dealing with medical privacy will be forwarded as soon as possible.

Cordially



H. S. Knight
Director

Mr. DRINAN. Well, it seems to me that that is very essential and very relevant to this whole thing. There is different language in the two bills. The administration bill is seemingly a bit more restrictive in that the Federal authority has to certify in writing that the information is needed to accomplish this purpose.

But, the bill filed by our distinguished chairman just says that you have to certify that the record is being sought for a legitimate Secret Service purpose. Assuming that this section survives, would you have any thoughts about making this particular certification worthwhile or meaningful?

Could we require that the information be given to the health provider by the Secret Service and that it be specific?

Mr. KNIGHT. Yes, sir. We can do that. As we have done previously before in the Financial Disclosure Act, we have drawn very tight internal guidelines as to how that is to be administered. At your request, we sent you a copy. We would be happy to do the same thing.

Mr. DRINAN. On the counterintelligence or positive intelligence, whatever that means, in the bill before us, I assume that in some instances, your agency cooperates with the FBI or the CIA if someone is threatening a foreign dignitary?

Mr. KNIGHT. Yes. That is a reasonable assumption.

Mr. DRINAN. Would you have any sentiments as to the provision here that foreign intelligence be exempt from the bill?

Mr. KNIGHT. I am not your best witness on that. I just am not qualified to respond.

Mr. DRINAN. Would any great disaster happen if, as advocated by a previous witness, we did not have this section?

Mr. KNIGHT. I think what this section does is preserve the status quo, basically.

Mr. DRINAN. And the bill does not preserve the status quo. So, we get back to the question that if it were dropped somewhere along the line, couldn't you develop ways within the meaning of the law, the purposes of the law, that would bring you the information that you need?

Mr. KNIGHT. I think we could do that, but I am not sure that that would be interpreted equally equitably and the same by all the hospital administrators and health professionals who would have to deal with this law.

Mr. DRINAN. They deal with your agency just like they deal with the local police. They would say, we have guidelines. We have a statute. From the statute they would have regulations or guidelines. I think that they would be happy to say that we know what we are doing. We do have strict statutory and administrative guidelines.

We do not have to treat the Secret Service as an exemption.

Mr. KNIGHT. Well, we would like to think that we should be treated as an exemption, given the responsibilities we have and for that purpose only.

Mr. BUTLER. If the gentleman would yield here, wouldn't we run into the problem, though, if we struck this section out, we wouldn't know what the situation was and that would therefore—I am thinking of an institution in which they have either a patient or an inmate, whatever capacity they might be there, that says to his favorite shrink, I'm going to kill my Congressman.

I've got a plan and so forth. And, absent this legislation, we would have some reservation—you, the physician, would have some reservation about whether you can communicate that information to the Secret Service with immunity.

I feel a real necessity, it seems to me, to—maybe we are discovering the status quo or whatever it is. But, we have got to articulate it once we undertake to legislate in this area.

Mr. DRINAN. The gentleman as usual made a perceptive comment. It is not an easy area. But, if an exemption to the basic principles of privacy is to be granted to the Secret Service, we have to think this thing out and we have to decide precisely how they are different in carrying out their role from the local police or from the FBI or from any other law enforcement group.

Thank you very much.

Mr. KNIGHT. Perhaps I can draw a differentiation from any other law enforcement group. We are not asking for this for our criminal work. We really need three things. We need to know the diagnosis, the prognosis, and the propensity for violence before we can make a decision.

Those are really what we are looking at and looking for. I think in that sense, as it relates to our protection, it does differentiate between ourselves and local police or State police.

Mr. DRINAN. All right. Thank you very much, sir.

Mr. PREYER. Thank you. Mr. Evans?

Mr. EVANS. Earlier, I believe you stated that you did not inform the individuals that you were investigating—of your investigation of them. But I thought at the same time, you also mentioned that you sometimes sent agents to the homes of these individuals to check on them.

Now, who do you inform?

Mr. KNIGHT. The fact of the matter is that many of these people, the parents or the brothers and sisters are very understanding of the subject's position and are very cooperative. In those instances, we would go to the residence and say, is he going to be in town this week and that sort of thing.

Does that answer your question? In other words, we do not inquire at the residence of every subject that we talk to.

Mr. EVANS. I understand that. Approximately how many individuals is the Secret Service responsible for protecting, domestic individuals, U.S. citizens?

Mr. KNIGHT. U.S. citizens, the number is 17. And, that will increase in the coming year when rumor has it that some of your colleagues will be running for President or Vice President and we have that responsibility also.

Mr. EVANS. How many agents do you have that would be involved in a protective function such as the advance planning along with the actual cohabitation with that individual or whatever?

Mr. KNIGHT. With all due respect, I would be happy to discuss that with you in whatever depth you wish, but not on the record because we have always not publicly announced how many people are assigned to protect any one individual, thinking that that may serve only those purposes of someone who has designs on penetrating that.

But, I would be happy to discuss it with you off the record.

Mr. EVANS. So, you would not be willing to state how many of your agents are trained to carry out some type of protective—

Mr. KNIGHT. That is a quite different question. The total number of agents at this time is 1,553 throughout 100 field offices, all of whom are trained to do the protective function.

Mr. EVANS. You have files currently on approximately how many individuals?

Mr. KNIGHT. My recollection is we have just completed extensive purging. The reason we had not before is because we were under instructions from the intelligence committees and the House Select Committee on Assassinations not to destroy any files. We now have total files of 27,000.

Mr. EVANS. Normally, this would be approximately the normal number of files you would have, given your procedures here as I understand, to keep files basically for 5 years?

Mr. KNIGHT. Given the openings of new cases and the purging of those cases, 25,000 approximately, yes.

Mr. EVANS. Are you aware of any problems that have resulted from a person learning of Secret Service access to their medical records?

Mr. KNIGHT. We have had agents assaulted when they learned of this, yes.

Mr. EVANS. What about problems that have been caused an individual whose medical record was accessed by the Secret Service?

Mr. KNIGHT. I am not sure I understand that.

Mr. EVANS. Well, let's say an individual whose records were sought out by the Secret Service and perhaps their employer became aware of the investigation and consequently perhaps, they were dismissed from their job, that type of thing.

Mr. KNIGHT. You put your finger on a very sensitive subject. If we are trying to reach a decision as to the potential dangers of this individual, from whom do you try and solicit this information? I would be frank and candid to admit to you that on a rare occasion when we perhaps interview an employer because there was no other source available, there have been rare occasions when retribution has taken place and the individual has lost his job.

We seek and search for alternatives to that all we can. No one would want, for example, to go into a neighborhood and say to all the neighbors, does George ever act odd, because then you put a stigma on there that is difficult to—perhaps never would be erased.

We are very, very sensitive to that, the problem being on rare occasions there is just no alternative but to do that in order to make an informed decision.

Mr. EVANS. Thank you, Mr. Chairman.

Mr. PREYER. Thank you.

We appreciate very much your testimony. You have a difficult job. You are assaulted by the Warren Commission, the Assassination Committee for not gathering enough information.

Civil libertarians attack you for gathering too much information. If you can keep each side equally unhappy, you are probably doing a good job. You should follow the advice of Herman Hickman, the old Yale football coach, in talking about alumni.

He said, "I just try to keep them sullen, but not mutinous."

You mentioned you would supply a set of your guidelines for us. Would you also supply for the record a copy of all the State laws and regulations that you feel restrict your ability to seek medical records?

Mr. KNIGHT. Yes, sir.

[The material requested follows:]

DEPARTMENT OF THE TREASURY
UNITED STATES SECRET SERVICE

WASHINGTON, D.C. 20223

DIRECTOR



1979

The Honorable
Richardson Preyer
Chairman
Government Information and
Individual Rights
Rayburn House Office Building
Washington, D.C. 20515

Attn: Bob Gellman

Dear Mr. Chairman:

On June 14, 1979, I testified before the Sub-Committee on the impact of the Medical Privacy Act upon the Protective intelligence operations of the United States Secret Service.

A request was made at that time for the Secret Service to compile the various state laws pertaining to the access of Medical/Mental Health Records. The attached binder contains what we believe to be the laws, regulations and/or State policies controlling access to this information.

I hope this will assist the Sub-Committee in its review of this proposed legislation. If the Secret Service can provide any further assistance in this regard, do not hesitate to call upon this Office.

Sincerely, .

H. S. Knight
Director

[Attachment available in subcommittee files.]



Mr. PREYER. I think that would be very useful.

Mr. BUTLER. Mr. Chairman, just one other question here.

What professional psychiatric staff do you have to evaluate this information before you make these critical decisions?

Mr. KNIGHT. We have no psychiatrists except the one on consultation with us now, which is an aberration and really does not respond to your question.

But what we have had done in the past 8 or 10 years is a series of outside people who could come in and look at our operation objectively and without exceptions, they said in this very difficult area, you are doing as good or better job than most of the professionals in the area.

Because when it comes down to the bottom line, when we are interested in someone because we think they pose a threat, really what we are asking people to do—and often, it is an individual agent on an individual basis—is to predict individuals' human behavior. And that is very difficult, as you know.

But to assure you that we are not overreacting, out of the 27,000 I mentioned, there are less than 400 in which we are really interested. The 27,000 came to our attention and we are waiting to purge the file.

Mr. BUTLER. Thank you.

Mr. PREYER. Thank you.

Again, we appreciate your testimony.

[Additional material supplied by witness follows:]



THE UNDER SECRETARY OF THE TREASURY

WASHINGTON, D. C. 20220

AUG 3 1979

Dear Mr. Chairman:

Reference is made to your letter dated June 21, 1979, regarding my June 14, 1979, appearance before your Subcommittee on Government Information and Individual Rights.

The transcript of my testimony and that of Director H. Stuart Knight has been edited and is being returned for your use.

In addition, you have requested clarification on three additional items.

1. What do "threaten", "unusual interest", and "consider dangerous" mean in this context? Do these people actually physically attack your protectees, or are you saying that those who threaten to attack your protectees are often mentally ill?

By the nature of its mission, the Secret Service must deal in terms of preventing an act of violence. To fulfill this mission we seek to determine the status of persons potentially dangerous to our protectees. In this sense, we are saying that the individuals who have threatened to attack our protectees are often mentally ill.

In any context/forum involving our protectees, "threaten" refers to just that - a direct or implied expression by a person to inflict harm on a protectee of the Service, whether that expression be manifested in a written or oral statement or by actions of the individual.

"Unusual interest" as well as "threaten" are identifiers by which we describe a subject's interest in our protectees. In the category of "unusual interest" no specific threat has necessarily been made, but the person demonstrated an interest/obsession in a protectee which by its content is uncommon or out of the ordinary. We are not referring to an individual who

may write to the President or otherwise exercise their First Amendment rights. In the instance of mental references, we ask the trained professionals to determine in their opinion what seems "unusual" and which may affect the safety of our protectees.

In our evaluation process we separately categorize those persons that through investigation we determine to be "dangerous." This determination is made with definite consideration given to not only an individual's current motivation and capability to carry out an attack, but also his propensity for action based on his mental stability. Statistical evidence is clear in supporting the determination that the majority of individuals the Secret Service considers dangerous to a protectee are mentally ill. Further, many of these individuals are also currently institutionalized in mental health facilities.

2. What percentage of people who have actually attacked your protectees could have been identified beforehand through their medical records?

There have been four attacks against Secret Service protectees in recent times. Three of the four, Lee Harvey Oswald, Lynette Fromme and Sara Jane Moore had a mental history which may have indicated a potential problem.

Lee Harvey Oswald's history was as a young teenager which would have made it subject to questionable interpretation and doubtful assistance.

Lynette Fromme and Sara Jane Moore both have histories of mental problems. Had these histories been available and evaluated along with their past actions and statements, a potential problem may have been recognized.

Arthur Bremer has never received any documented professional help although his actions leading up to the assault on Governor Wallace, as outlined in his diary, were indications of mental instability.

It is difficult to determine if any of the above individuals could have been identified through their mental records. Certainly, the chances of identifying

such individuals would increase if their mental conditions were known beforehand and considered in the evaluation process.

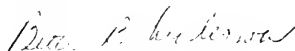
3. What percentage of the people listed in your files as potentially dangerous do actually attack, or take any overt action in planning to attack, your protectees?

The proper measure of our productivity or "success" is not in percentages or numbers of individuals whose names are in our files and who actually do make an attack or some other overt action. It is rather the extent to which the Secret Service is successful in preventing any attack or overt act from happening at all. That is the purpose in gathering the information and maintaining the files in the first place.

We know of no way to measure the number of attempts or overt acts that "might have happened" but did not. An underlying premise to our prevention program is that an individual's awareness of our knowledge of his intent may serve as a deterrent to any planned action he may have.

Again, let me thank you and your subcommittee for the opportunity to testify on this important and meaningful legislation.

Sincerely,



Bette B. Anderson

The Honorable
Richardson Preyer, Chairman
Subcommittee on Government Information
and Individual Rights
Committee on Government Operations
House of Representatives
Washington, D.C. 20515

Enclosure



DEPARTMENT OF THE TREASURY
WASHINGTON, D.C. 20220

ASSISTANT SECRETARY

SEP 17 1979

Re: Proposed Federal Privacy of Medical Records Act

Dear Mr. Chairman:

On June 14, 1979, at the invitation of the Subcommittee on Government Information and Individual Rights, Bette B. Anderson, Under Secretary of the Treasury, and H. Stuart Knight, Director of the Secret Service, presented the views of the Treasury Department with respect to H.R. 2979, the proposed Federal Privacy of Medical Records Act. During the course of testimony, the need of the Secret Service to maintain contact with mental institutions in order to fulfill its protective functions was stressed.

The purpose of this letter is to supplement that testimony by explaining in more detail how we believe one particular section of H.R. 2979 should be altered to take account of the Secret Service's needs. As now written, Section 102(b) is designed to preserve the ability of state and local authorities to restrict access to certain medical records by creation of laws that add to the protections contained in the Medical Records Act. Insofar as this section leaves the states free to add restrictions on access by private persons and state and local authorities, we do not have a direct interest in the matter.

We do have a concern, however, with the potential impact of this section on Secret Service or other Federal agencies' access to medical records. We do not believe that your Committee intends to alter the status quo in that area. Unfortunately, the current wording of Section 102(b) does not make this intention clear.

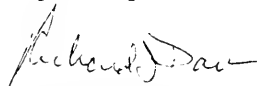
We believe that this portion of the Act would be significantly clarified and improved by the addition of the following Subsection (c) to Section 102.

§102(c) Nothing in Subsection (b) shall be construed to curtail the present authority, whether expressed or implied, of any Federal agency to gain access to medical records.

Thank you for giving us the opportunity to express our views on

this matter. Should you have any questions regarding this proposal, please do not hesitate to contact us.

Respectfully,

A handwritten signature in dark ink, appearing to read "Richard J. Davis", written in a cursive style.

Richard J. Davis
Assistant Secretary
Enforcement & Operations

The Honorable Mr. Richardson Preyer
Chairman, House Subcommittee on Government
Information and Individual Rights
B349 Rayburn House Office Building
Washington, D. C. 20515

Mr. PREYER. The subcommittee will stand adjourned.
[Whereupon, at 12:55 p.m., the subcommittee adjourned, to recon-
vene subject to the call of the Chair.]

PRIVACY OF MEDICAL RECORDS

MONDAY, JULY 9, 1979

HOUSE OF REPRESENTATIVES,
GOVERNMENT INFORMATION
AND INDIVIDUAL RIGHTS SUBCOMMITTEE
OF THE COMMITTEE ON GOVERNMENT OPERATIONS,
Washington, D.C.

The subcommittee met, pursuant to notice, at 10:05 a.m., in room 2247, Rayburn House Office Building, Hon. Richardson Preyer (chairman of the subcommittee) presiding.

Present: Representatives Richardson Preyer, Robert F. Drinan, Thomas N. Kindness, and John N. Erlenborn.

Also present: Timothy H. Ingram, staff director; Robert M. Gellman, associate counsel; and Thomas G. Morr, minority professional staff, Committee on Government Operations.

Mr. PREYER. The committee will come to order. Today we continue consideration of legislation to protect the confidentiality of medical records. This is our fifth day of hearings, and on Saturday we will be holding another hearing in Indianapolis, where the University of Indiana Medical School, the largest in the country, is located. The hearing process will probably not be completed until September.

I think that the efforts we are making on this legislation are valuable. Privacy laws can have unexpected effects, and it takes considerable time and effort to identify all of the consequences in advance. This is one lesson we have learned from other privacy laws.

Unfortunately, this experience with other privacy laws is only partially relevant to medical records privacy. We know from the work of the Privacy Protection Study Commission that different types of controls are appropriate for different types of records.

A medical record privacy law, for instance, must take into account the unique and critical relationship between doctor and patient. This means that we cannot simply adopt the approach used in privacy laws for bank records, for example, or education records, or other types of records.

Our first witness today is Mr. John C. Keeney, who is the Deputy Assistant Attorney General from the Department of Justice's Criminal Division, and he is accompanied, I understand, by Mr. Francis M. Mullen, Jr., from the Federal Bureau of Investigation's Criminal Investigation Division.

We welcome you, Mr. Keeney and Mr. Mullen, this morning, and we look forward to your statements.

STATEMENT OF JOHN C. KEENEY, DEPUTY ASSISTANT ATTORNEY GENERAL, CRIMINAL DIVISION, DEPARTMENT OF JUSTICE; ACCOMPANIED BY ABBE LOWELL, SPECIAL ASSISTANT TO THE DEPUTY ATTORNEY GENERAL; FRANCIS M. MULLEN, JR., INSPECTOR-DEPUTY ASSISTANT DIRECTOR, CRIMINAL INVESTIGATION DIVISION, FEDERAL BUREAU OF INVESTIGATION; AND PAT WATSON, INTELLIGENCE DIVISION, FBI

Mr. KEENEY. Mr. Chairman, if it is all right, I would like to have at the table Mr. Abbe Lowell, Special Assistant to the Deputy Attorney General, who is very familiar with the Financial Privacy Act and would be helpful in answering any questions that might show the interrelationship between your bill and the Financial Privacy Act.

Mr. PREYER. Fine.

Mr. MULLEN. Mr. Chairman, if we could also have Mr. Pat Watson, from the FBI Intelligence Division, with regard to foreign intelligence questions.

Mr. PREYER. Good to have you here, Mr. Watson.

Mr. KEENEY. Mr. Chairman, if I may, I would like to offer my statement in full for the record, and then I would like to discuss some of the highlights of the statement, and I would also like to go into some of the matters that are unfortunately not reflected in our statement. They are matters of four areas of general concern to the Department of Justice. I realize, and I apologize for going into these things without having them in the formal statement, but we would be very pleased to submit them in writing at a later date, and if the chairman and the committee desires, we would be pleased to come back before the committee, either before staff, or before the membership, and answer any questions they might have with respect to this additional material.

Mr. PREYER. Fine. Without objection, your statement will be made part of the record, and you may proceed as you indicated.

[Mr. Keeney's prepared statement follows:]



Department of Justice

STATEMENT OF
JOHN C. KEENEY,
DEPUTY ASSISTANT ATTORNEY GENERAL,
CRIMINAL DIVISION,
UNITED STATES DEPARTMENT OF JUSTICE
BEFORE THE
SUBCOMMITTEE ON GOVERNMENT INFORMATION AND INDIVIDUAL RIGHTS,
COMMITTEE ON GOVERNMENT OPERATIONS,
UNITED STATES HOUSE OF REPRESENTATIVES
CONCERNING
FEDERAL MEDICAL RECORDS PRIVACY LEGISLATION

July 9, 1979

Mr. Chairman and Members of the Subcommittee, I am pleased to be here today to present the views of the Department of Justice on medical records privacy legislation. Accompanying me is Francis M. Mullen, Jr., Inspector and Deputy Assistant Director of the Criminal Investigation Division, Federal Bureau of Investigation. Mr. Mullen will be available to respond to questions.

Last year, we worked closely with the Congress in the consideration of the Right To Financial Privacy Act of 1978. This year we are eager to take part once again in further efforts to insure that the privacy of Americans is properly protected. In summary, we favor legislation to safeguard the privacy rights of citizens in medical records pertaining to them. As the Subcommittee recognizes, however, access to medical records can be crucial in many legal proceedings and law enforcement investigations. It is extremely important, therefore, that medical records legislation carefully balance privacy interests against legitimate law enforcement needs.

The Subcommittee has specifically requested a discussion of the various ways in which medical records are used by the Department of Justice. Before proceeding to specific provisions of the two major medical records privacy bills before the Subcommittee, therefore, let me review some of the circumstances in which the Department seeks medical information.

Medical records are most frequently utilized in connection with investigations of fraud and abuse involving federal medical assistance

programs. In recent years, we have initiated numerous criminal investigations and prosecutions of Medicare and Medicaid fraud. In fact, the various types of programs fraud have become a priority enforcement area to which expanded investigative and prosecutorial resources have been devoted. Typically, Medicare and Medicaid fraud cases involve inflated charges for medical services or charges for services that were not rendered. Major investigations may require review of records pertaining to hundreds of patients as well as follow-up interviews to determine whether services described in medical records were in fact rendered. While these cases most often involve no wrongdoing on the part of patients, some frauds are perpetrated through a conspiracy between service providers and patients. Often, it is only through careful analysis of medical records that we can determine precisely who is responsible for a fraudulent scheme. An investigation of a single physician, for example, may develop into an investigation of a wide-spread conspiracy involving several health professionals, medical facility staff, numerous patients, and perhaps even government employees responsible for administering medical assistance programs.

Another area of government program fraud involves federally-sponsored disability programs which provide benefits ranging from early retirement for federal employees to black-lung benefits for disabled coal miners. In such cases, patients may be acting in collusion with unscrupulous medical service providers to obtain benefits through submission of falsified or inaccurate medical records. The need for access to medical records in such cases is obvious.

With respect to fraud against the government, the Subcommittee should note that the Department is working closely with the newly appointed Inspectors General in an effort to reduce program fraud. While we have not in the past prosecuted large numbers of cases in which the subject of medical records is the principal defendant, the number of such cases is expected to increase with increased investigative efforts by Inspectors General. Further, the Department is currently exploring alternatives to the criminal justice system for use in cases which, because of the small amount of loss involved or extenuating circumstances, do not justify criminal prosecution.

Medical records are also used in connection with investigation and prosecution of controlled substances cases involving unlawful use or sale of controlled drugs by the health professionals who are registered to prescribe or dispense such substances. Because of recordkeeping requirements, such illegal sales or uses are often masked by falsified entries indicating that the drugs were legitimately dispensed to patients. In these instances, only by analysis of medical records can it be determined whether the entries are false. A person's medical condition, for example, could be reviewed to determine whether a prescription was appropriate in a given case. The patient might also be interviewed to determine whether he or she in fact received the drugs reflected by the records.

Most controlled substances cases involve wrongdoing by persons other than the subject of medical records. An example of crime by the health professional registered to prescribe controlled substances is the Department's current investigation of a physician who last year prescribed amphetamines totalling approximately three percent of the entire United States amphetamine production. Review of medical records in that case shows that not only did the physician fail to perform any examination of the "patients" seeking amphetamine prescriptions, but that if he had conducted physical examinations he would have detected medical conditions in several patients which made their use of amphetamines life-threatening.

In some controlled substances cases, however, offenses are perpetrated by patients. A good example of this latter type of case is the recent Preludin investigation which resulted in the conviction of the head of what the news media labelled "The Fat Lady Drug Ring." By way of background, Preludin is an appetite suppressant which is also popular among drug addicts for use in conjunction with heroin. In the Predulin case, the defendant recruited a number of overweight women who were employed to visit as many private physicians as possible to obtain prescriptions for Preludin. The drugs obtained in this manner were then sold to addicts. Obviously, in such a case, access to medical records can be helpful in establishing the pattern of the offense by documenting the frequency of visits, the quantity of drugs prescribed and the seriousness of the patients' condition both before and after treatment.

In another area, medical records are employed in connection with enforcement of federal health and safety laws. In some cases, medical records are the best evidence that employees or other persons have been exposed to toxic substances or emissions. An example of the use of medical records in such circumstances was the Kepone investigation near Richmond, Virginia. In this case, illness among plant employees was the first indication that the pesticide being manufactured there was being handled in such a way as to constitute a threat to public health.

Some fraud schemes involve the sale of worthless products which are claimed to restore health. The sales pitch for the product may include testimonials by persons who claim that use of the product brought about a remission of arthritis, cancer, or whatever illness is supposedly cured by the product. Reference to medical records of those giving the testimonials can be important to establish that there was a misrepresentation in connection with the sale.

Medical records are sometimes instrumental in locating a fugitive. The classic case is the armed robber who is wounded in the course of the robbery. An alert to emergency rooms and clinics can lead to apprehending the fugitive when he seeks medical treatment. There are other applications, however, as is pointed out by the case of the fugitive on the FBI's list of ten-most-wanted fugitives whose medical records showed him to be a diabetic; an alert to dispensers of insulin in the area resulted in the fugitive's capture.

Psychiatric and psychological records are obviously important in connection with criminal trials in which the defendant pleads insanity. Such records sometimes show a long history of mental disorder with the result that the government does not waste resources opposing the defense. In other cases, however, such records may reveal that a defendant has a history of feigning mental disorder to escape responsibility for his acts; such records are, of course, highly relevant to the insanity proceeding.

Homicide cases can require resort to medical records of either the victim or the suspected perpetrator. This is particularly true where an individual with medical training commits a very sophisticated murder which can only be established by analysis of the victim's medical records. Manslaughter investigations, as in cases where the charge is homicide by motor vehicle while under the influence of alcohol or drugs, sometimes require analysis of medical records of the defendant. Since homicide jurisdiction of the federal government is limited, our need for access to records in connection with homicide cases is of course, less frequent than that of state and local law enforcement authorities.

Child abuse investigations obviously require access to medical records; in some cases, medical records are the best evidence of child abuse. The same is true of medical-related crimes such as euthanasia and illegal abortions. Of course, investigation of such offenses is generally a state matter unless the offense occurs on a federal enclave.

An infrequent but nonetheless important need for medical records develops in connection with hostage situations such as terrorist incidents where a psychiatric profile of the terrorist has sometimes made it possible to avoid any loss of life. Where hostages have serious medical conditions, it is also important to have information regarding those conditions as it enables law enforcement authorities to negotiate for the release of infirm individuals or to supply the medical needs of hostages.

Medical records are sometimes reviewed in connection with background investigations of applicants for sensitive federal positions. Such employees, including attorneys and investigators of the Department of Justice, are routinely asked as item 19 of Standard Form 86 whether they have ever had treatment for a mental condition and, if so, to describe the condition and treatment. Only by reference to medical records can the representations in the application be verified.

A related use of medical records is in connection with informants. Depending upon the sensitivity of the informant's mission, it may be important to determine whether he or she is emotionally stable or free of addiction to drugs.

The need for medical records arises in many different ways during criminal trials. In some cases, defendants offer an alibi defense claiming that they were hospitalized at the time the crime involved was committed. In other cases, a defendant may claim that he or she suffers physical disabilities that would make it impossible to carry out the acts necessary to commit the offense. Introduction of medical records may also be appropriate if they establish that a given witness suffers some medical condition substantially affecting his or her ability to observe, recall or relate the events that are the subject of his or her testimony.

In the civil area, medical records are essential in most Federal Tort Claims Act cases in which individuals are suing the government for physical injuries suffered as the result of alleged negligence by the government. It should be noted that many of these cases are settled without the filing of a lawsuit thus requiring access to medical records through mechanisms other than the Federal Rules of Civil Procedure which are not generally applicable until a complaint is filed.

Medical records are also important in many tax cases involving questionable tax deductions for alleged medical necessities. Further, in cases of failure by health professionals to report income, a limited review of medical-related records may be necessary to compute the tax evader's actual income.

In the very important foreign counter-intelligence area, medical records are sometimes used. One use is in connection with identification. Sometimes fragmentary information is obtained identifying an agent of a foreign power. It may be learned, for example, that the agent was hospitalized at a certain medical facility at a particular time for a particular condition. Or it may be that we know only that an agent of an foreign power suffers from a particular medical condition. Medical records can, therefore, assist in positively identifying the agent. In penetration cases, it may be learned that an enemy power is seeking to recruit a high-level government official to operate as a spy within our government structure or that a sensitive government organization has already been penetrated by an enemy agent. Anything that can be learned about the physical condition and emotional stability of such an individual could be exceedingly important. Again, such needs are infrequent, but they do occur.

While the above discussion of medical records is not intended to be exhaustive, I believe it does cover most of the common uses by the Department of Justice. As you can see, access to medical records is essential in many situations and is important to arriving at a just result in many other circumstances.

Proceeding now to the two bills receiving primary consideration by the Subcommittee, let me attempt a capsule summary. The Administration's proposal, H.R. 3444, is a rather direct transfer of the procedures of the Right to Financial Privacy Act of 1978 to medical records; Chairman Preyer's bill, H.R. 2979, is substantially similar to the Financial Privacy Act but departs in several important respects. Of the two bills, the Department favors the Administration proposal as more nearly achieving a proper balance between law enforcement needs and privacy interests.

In conclusion, I should note that the Department is presently reviewing the experience we are gaining under the Right to Financial Privacy Act which went into effect on March 10 of this year. Our preliminary analysis indicates that amendments may be required in that Act. Because both H.R. 3444 and H.R. 2979 parallel the Financial Privacy Act in many respects, we hope to provide the Subcommittee with a further statement in the near future reporting on our experience. In the meantime, we appreciate this opportunity to discuss our use of medical records and hope the information we have provided will be helpful to the Subcommittee in arriving at a measure that will balance individual privacy rights against legitimate law enforcement needs.

Thank you.

Mr. KEENEY. Mr. Chairman, last year, we worked closely with the Congress, we in the Department of Justice, in the consideration of the Right to Financial Privacy Act of 1978. This year, we are eager to take part once again in further efforts to insure that the privacy of Americans is properly protected. In summary, we favor legislation to safeguard the privacy rights of citizens in medical records pertaining to them. As the subcommittee recognizes, however, access to medical records can be crucial in many legal proceedings and law enforcement investigations. It is extremely important, therefore, that medical records legislation carefully balance privacy interests against legitimate law enforcement needs. You have specifically requested a discussion of the various ways in which medical records are used by the Department of Justice. Let me review some of the circumstances, and the first category is probably one of the most important categories, which is utilization in connection with investigations of fraud and abuse involving Federal medical assistance programs. In recent years, we have initiated numerous criminal investigations and prosecutions of medicare and medicaid fraud. In fact, the various types of program fraud have become a priority enforcement area to which expanded investigative and prosecutorial resources have been devoted. Typically, medicare and medicaid fraud cases involve inflated charges for medical services or charges for services that were not rendered.

Major investigations may require review of records pertaining to hundreds of patients as well as follow-up interviews to determine whether services described in medical records were in fact rendered. While these cases most often involve no wrongdoing on the part of patients, some frauds are perpetrated through a conspiracy between service providers and patients. Often, it is only through careful analysis of medical records that we can determine precisely who is responsible for a fraudulent scheme. An investigation of a single physician, for example, may develop into an investigation of a widespread conspiracy involving several health professionals, medical facility staff, numerous patients, and perhaps even Government employees responsible for administering medical assistance programs.

Another area of Government program fraud involves federally sponsored disability programs which provide benefits ranging from early retirement for Federal employees to black-lung benefits for disabled coal miners. In such cases, patients may be acting in collusion with unscrupulous medical service providers to obtain benefits through submission of falsified or inaccurate medical records. The need for access to medical records in such cases is obvious.

With respect to fraud against the Government, the subcommittee should note that the Department is working closely with the newly appointed Inspectors General in an effort to reduce program fraud. While we have not in the past prosecuted large numbers of cases in which the subject of medical records is the principal defendant, the number of such cases is expected to increase with new investigative efforts by Inspectors General.

Medical records are also used in connection with investigation and prosecution of controlled substances cases involving unlawful use or sale of controlled drugs by the health professionals who are

registered to prescribe or dispense such substances. Because of recordkeeping requirements, such illegal sales or uses are often masked by falsified entries indicating that the drugs were legitimately dispensed to patients. In these instances, only by analysis of medical records can it be determined whether the entries are false.

In another area, medical records are employed in connection with enforcement of Federal health and safety laws. In some cases, medical records are the best evidence that employees or other persons have been exposed to toxic substances or emissions. The Kepone investigation in the Richmond area is an example of this situation.

Some fraud schemes involve the sale of worthless products which are claimed to restore health. Reference to medical records of those giving the testimonials can be important to establish that there was a misrepresentation in connection with the sale.

As Mr. Mullen points out, medical records are sometimes instrumental in locating a fugitive.

Psychiatric and psychological records are obviously important in connection with criminal trials in which the defendant pleads insanity. Such records sometimes show a long history of mental disorder with the result that the Government does not waste resources opposing the defense. In other cases, however, such records may reveal that a defendant has a history of feigning mental disorder to escape responsibility for his acts; such records are, of course, highly relevant to the insanity proceeding.

Homicide cases can require resort to medical records of either the victims or the suspected perpetrator. This is particularly true where an individual with medical training commits a very sophisticated murder which can only be established by analysis of the victim's medical records. This, again, is an area discussed to some extent in Mr. Mullen's statement. An infrequent but nonetheless important need for medical records develops in connection with hostage situations such as terrorist incidents where a psychiatric profile of the terrorist has sometimes made it possible to avoid any loss of life. Where hostages have serious medical conditions, it is also important to have information regarding those conditions as it enables law enforcement authorities to negotiate for the release of inform individuals or to supply the medical needs of hostages.

Medical records are sometimes reviewed in connection with background investigations of applicants for sensitive Federal positions. Such employees, including attorneys and investigators of the Department of Justice, are routinely asked as item 19 of standard form 86 whether they have ever had treatment for a mental condition and, if so, to describe the condition and treatment. Only by reference to medical records can the representations in the application be verified.

A related use of medical records is in connection with informants. Depending upon the sensitivity of the informant's mission, it may be important to determine whether he or she is emotionally stable or free of addiction to drugs.

The need for medical records arises in many different ways during criminal trials. In some cases, defendants offer an alibi defense claiming that they were hospitalized at the time the crime involved was committed, as one example. In other cases, a defend-

ant may claim that he or she suffers physical disabilities that would make it impossible to carry out the acts necessary to commit the offense. Introduction of medical records may be appropriate if they establish that a given witness suffers some medical condition substantially affecting his or her ability to observe, recall, or relate the events that are the subject of his or her testimony.

Also in the civil area, medical records are essential in most Federal Tort Claims Act cases in which individuals are suing the Government for physical injuries suffered as the result of alleged negligence by the Government. It should be noted that many of these cases are settled without the filing of a lawsuit, thus requiring access to medical records through mechanisms other than the Federal Rules of Civil Procedure which are not generally applicable until a complaint is filed.

Medical records are also important in many tax cases involving questionable tax deductions for alleged medical necessities.

In the very important foreign counterintelligence area, medical records are sometimes used. This again has been developed in Mr. Mullen's statement.

While this discussion of medical records is not intended to be exhaustive, Mr. Chairman, I believe it does cover most of the common uses by the Department of Justice, and, as you can see, access to medical records is essential in many situations and is important to arriving at a just result in many other circumstances.

Proceeding now to the two bills receiving primary consideration by the subcommittee, let me attempt a capsule summary. The administration's proposal, H.R. 3444, is a rather direct transfer of the procedures of the Right to Financial Privacy Act of 1978 to medical records; Chairman Preyer's bill, H.R. 2979, is substantially similar to the Financial Privacy Act but departs in several important respects. Of the two bills, the Department favors the administration proposal as more nearly achieving a proper balance between law enforcement needs and privacy interests.

I should note that the Department is presently reviewing the experience we are gaining under the Right to Financial Privacy Act, which went into effect on March 10 of this year. Our preliminary analysis indicates that amendments may be required in that act. Because both bills parallel the Financial Privacy Act in many respects, we will provide the subcommittee with a further statement in the near future reporting on our experience.

Mr. Chairman, we request, if we may, the opportunity to submit detailed comments on H.R. 2979 in the near future. We will abide by whatever reasonable deadlines you set. Meanwhile, I would like, if I may, to highlight the areas we have focused on as being of primary concern to the Department of Justice.

We apologize, Mr. Chairman, again, for submitting these comments without having them available to you in written form, but, because of that, we would be pleased to return at a later date to respond to questions of either the committee or staff with respect to the four areas I am about to discuss.

First, Mr. Chairman, we are concerned about those provisions of H.R. 2979 which would depart from the Financial Privacy Act by placing restrictions upon Federal grand jury subpoenas. As you know, the Federal grand jury is a constitutionally authorized and

required mechanism for investigating and bringing felony charges in the Federal system. So important is it to safeguard this process from litigious interruption and delay that the Supreme Court of the United States has repeatedly held that the grand jury process should not be hampered by minitrials, evidentiary hearings, and other disruptive proceedings. In *United States v. Calandra*, 414 U.S. 338 (1974), the Supreme Court even held that the victim of an allegedly unconstitutional search and seizure, who would clearly have standing at trial to challenge the introduction of the seized evidence, would, nevertheless, not be heard to protest its introduction and use before the grand jury. Because the statutory rights to prenotification and standing that would be created cannot claim to rest on any greater privacy grounds than a claim of unconstitutional search and seizure, it would be anomalous and would produce inconsistent results if Federal grand juries were subject to the requirements of a new medical records privacy law.

In addition to the unique legal and constitutional status which the Federal grand jury occupies, it is protected by rules insuring the secrecy of its proceedings. Expanded notice and challenge rights in the grand jury context could seriously jeopardize the rule of secrecy, and in so doing, violate the privacy rights of individuals being investigated. Further, Federal grand juries are already subject to the supervision of U.S. district courts.

A second major concern with H.R. 2979 is the showing required to prevail after a challenge to access is filed, or to secure a court order delaying notice. Specifically, the bill would require "reasonable cause" to believe the records are relevant to the investigation and a finding that "the Government authority's need for the record in the inquiry outweighs the individual's privacy interest." Both of these requirements seem inappropriate given the fact that they must be met during the investigatory stage of a proceeding. In this regard, "reasonable cause" is sometimes read as being equivalent to "probable cause" which is the standard of proof that must be shown to obtain an indictment at the conclusion of an investigation. At the preindictment stage, therefore, the information available to the Government is necessarily often less than probable cause. We would urge the subcommittee, therefore, that a standard no higher than "reason to believe," "reasonable belief" or "reasonable grounds to believe" be imposed by any medical records privacy bill. As the subcommittee is aware, the Financial Privacy Act uses the term "reason to believe."

We are also concerned about the notion of the balancing test requiring the court to weigh Government need for the record against the individual's privacy right. Again, at the investigatory stage of a proceeding the Government is not in possession of all the facts necessary to establish its "need" for a record; in most cases, it can only show relevance to a legitimate law enforcement inquiry. Under H.R. 2979, however, the Government may meet its burden of proving relevance but still be denied access. Such a result seems unwarranted.

Further, the balancing test poses enormous practical difficulties. First, the scope of the balancing inquiry is unclear. It might include the type of investigation in connection with which the record is sought with greater need ascribed to felony than to misdemeanor

investigations. The need could be considered to vary depending upon the seriousness of the felony or misdemeanor offense with more weight accorded an investigation into an offense which carries a punishment of 10 years' imprisonment than to one punishable by 5 years' imprisonment. The number of counts being considered may be determined to make a difference. The past criminal convictions of the suspected offender could be taken into account. On the other side of the balance, does every person have an equal privacy interest in his or her medical records regardless of the information they contain, or does an individual's privacy interest vary, depending upon the sensitivity of the information in the medical record, that is, does A have greater privacy rights in his medical records than does B because A's records reflect treatment for a social disease while B's records only reflect an appendectomy.

Even if painstakingly rewritten, the balancing test would impose a substantial burden upon Federal courts which would, in most cases, find it necessary to review both the medical records sought and a detailed statement of the Government's case in order to determine whether the need for the medical records outweigh privacy interests. No such test is used in the Financial Privacy Act, and I believe it should be deleted from this bill. We believe that a person's right to privacy in records is the right to require that the Government be able to demonstrate the legitimacy of its investigation and the relevancy of the records thereto. Once such a showing has been made, the Government should be permitted access.

An additional point is the need for an exception, similar to section 105(b)(18) of H.R. 3444, to cover medical records maintained by the U.S. Bureau of Prisons. It should be noted that the status of a person incarcerated in a Federal penitentiary is quite different from that of other citizens. Prisoners have many restrictions on their rights as the result of penal laws and regulations. Further, a prisoner's medical records are very often kept together with all other penal records as the institution is responsible for overseeing virtually every aspect of an inmate's life. The subcommittee should also be aware that the Department is currently developing standards for increased access by prisoners to records relating to them.

There are special problems in restricting law enforcement access to prison records. In investigating crimes committed within the institution, for example, it is very unusual for any inmate to cooperate with the investigation. Documents, therefore, are more important in such investigations than in normal cases. Further, there is a clear need for prison officials to control drug use by inmates; medical records are important in identifying potential drug problems and in taking action to close off the flow of drugs into the facility. In short, we believe that application of the bill to medical records of Federal prison facilities is inappropriate.

Finally, I anticipate that we will suggest to the committee the desirability of including in the bill provision for a formal written request which would authorize FBI access to medical records.

Mr. Chairman, that completes my remarks, and my colleagues and I are available to answer any questions this subcommittee would like to ask.

Mr. PREYER. Thank you very much, Mr. Keeney, and we will look forward to receiving information on your experience under the Financial Privacy Act and the other areas you mentioned.

Mr. Mullen, would you care to give us your statement at this time, before we ask questions, if that is agreeable to the committee?

Mr. MULLEN. Yes, Mr. Chairman, I have a brief five page statement. However, I ask that it be entered in the record, and I will touch on two points, if I may, before the questions.

No. 1, the FBI, for its part, would like to see some emergency access to medical records in situations such as the taking of a hostage, where there is imminent danger to loss of life. I can specifically cite a case in New Orleans where an individual was holding a nurse with the weapon pointed to her head, threatening to kill her and another individual—we had the psychiatrist of the gunman right on the scene, telling us what steps we should take in attempting to effect the apprehension—having immediate access to the records led to the successful conclusion of the case. So, in a situation like that, if we had a means of obtaining the information immediately, it could lead to prevention of loss of life.

In connection with our fugitive investigations, often the FBI will circularize information regarding a fugitive to various doctors or hospitals and, should a fugitive seek a certain type of medical treatment, we could be notified. I would like to make available to the committee two examples of this type of circularization.

One is Billie Dean Anderson, who was shot and killed in a shootout on Saturday by an FBI agent. Prior to his death we circularized about 2,500 medical facilities describing his physical condition in the event he should seek medical treatment at one of the facilities.

In another, 10 most wanted fugitive Willie Foster Sellers had a certain dental problem, and we put an article in a dental magazine, should he seek treatment for his problem. In neither case did the circularization lead to the apprehension of the fugitive, but I cite them as an example of the way we use medical information.

That is my only comment at this point, Mr. Chairman. I will be happy to answer any questions you may have.

[Mr. Mullen's prepared statement follows:]

OFFICE OF THE DIRECTOR



UNITED STATES DEPARTMENT OF JUSTICE
FEDERAL BUREAU OF INVESTIGATION

WASHINGTON, D.C. 20535

STATEMENT OF

FRANCIS M. MULLEN, JR.

FEDERAL BUREAU OF INVESTIGATION

BEFORE THE

SUBCOMMITTEE ON

GOVERNMENT INFORMATION

AND INDIVIDUAL RIGHTS

HOUSE OF REPRESENTATIVES

JULY 9, 1979

Mr. Chairman and distinguished members of this Committee:

Judge Webster has asked me to convey his regrets in not being able to testify before you today. He has requested that I appear before you in his absence to discuss the proposed amendment to the Privacy Act of 1974 and how its passage could be expected to impact on the FBI.

Let me say at the outset that the FBI as an organization supports the efforts of Congress in attempting to insure that the American public's fundamental right of privacy is protected. In this regard, we agree that the confidential medical information of an individual must be adequately protected from unauthorized access and use. Accordingly, the FBI supports the passage of this bill but in so doing, would like to point out that its adoption could present, as has the Right to Financial Privacy Act of 1978, certain problems for the FBI and the law enforcement community in general.

As a matter of information, the FBI makes far less use of information for an individual's medical record than most people might think. In the relatively few instances where such information is obtained, we exercise the utmost restraint and insist that our personnel hold a person's right to medical

privacy in the highest regard. To my knowledge there has never been an allegation brought to our attention concerning any FBI misuse of an individual's medical record.

Where medical records are reviewed, they are done so most often in applicant investigations. When medical information is required, a signed "release" or waiver" is provided by the applicant. Since the proposed legislation provides for the disclosure of medical information upon authorization of the individual, it should have virtually no impact on our background investigations.

Another area of responsibility where we have occasion to seek medical record information is in locating fleeing felons. I must point out, however, that by no means do we routinely attempt to obtain a fugitive's medical history. Such information is pursued in only a relatively small number of cases and in only compelling instances involving the most dangerous subjects. In such cases, it is often crucial that we have ready access to the fugitive's medical history. This information is paramount, particularly when the subject has a serious medical problem, suicidal tendencies, psychiatric disorder, narcotics addiction, or other condition. Armed with that information our Agents can more effectively conduct their inquiries and eventually plan the

necessary apprehension in such a way that the risk of injury, death, or property loss is reduced to a minimum. This medical information will help to enable our Agents to properly respond to any emergency situation arising out of an arrest. A person's susceptibility to an epileptic seizure, heart attack, or narcotics shock, etc. are examples of such situations, which if properly handled, could be life saving. Being forewarned of a possible suicide attempt or other violent action by a subject could likewise be extremely important.

Additionally, acquiring medical information concerning a fugitive often leads to the development and pursuit of important investigative leads which result in the subject's early arrest. Of course, these early arrests reduce the threats placed on the safety and well-being of the general public as a whole.

An example of the above is in our investigation to locate "Ten Most Wanted Fugitive" Willie Foster Sellers, who was recently apprehended at Atlanta, Georgia. Our lengthy investigation developed information indicating that Sellers was suffering from diabetes, chronic urinary, and dental problems requiring continued medication. Recognizing Sellers would no doubt seek medical assistance while at large, our Agents canvassed

numerous hospitals, doctors, and dentists, etc. in the Southeastern region of the country in an effort to solicit information as to his whereabouts. While this undertaking failed to contribute to Sellers' apprehension, the investigative possibilities developed as a result of Sellers' medical history required thorough exploration.

The FBI hopes that this proposed legislation will not inhibit health care providers and persons associated with medical care facilities in furnishing information to us in ongoing investigations.

This hesitancy or reluctance has been continually felt in connection with the Right to Financial Privacy Act of 1978. In this regard, despite the establishment of good faith compliance defenses in the Right to Financial Privacy Act, many institutions have not been forthcoming with financial records, which under the Act, should be available to the law enforcement community. It has been our experience that many in the financial community hesitate to provide necessary financial information to us because of their reluctance to accept the risk of possible civil liability.

Financial institutions themselves are reluctant to furnish us with information and are often uncertain as to how much data they can provide in reporting a criminal offense. In many situations, therefore, crimes go unreported that would normally be reported to us for investigation.

Although this legislation does not include a provision for mandatory disclosure for emergency situations, H.R. 3444 provides an expedited procedure to facilitate access. In an emergency situation if the medical facility did not respond, serious injury could result, a life be lost, a fugitive successfully escape, or substantial property damage occur while our Agents are required to obtain a search warrant or other documents required for the release of the necessary information. It is our contention that custodians of medical records should accede to formal official certified requests of law enforcement authorities in emergency situations.

This concludes my statement. If you or the members of this Committee have any questions at this time, I would be happy to answer them.

Mr. PREYER. Thank you very much for your testimony.

When the Justice Department or the FBI seeks to obtain medical records today, do you usually do it with the consent of the patient or with the cooperation of the recordkeeper, or do you do it through subpoena?

Mr. MULLEN. I will take that question. In our applicant investigations, it is always with the consent of the individual. We obtain a waiver to obtain a medical record in connection with applicant investigations.

In other instances it may be with or without the consent of the patient. I can cite specific examples. We have in one city an auto insurance fraud investigation, making fraudulent claims on insurance, and in this particular city the claims on insurance are 100 percent higher than any city of comparable size. This is resulting in the loss of millions of dollars to the public, and in this case we were able to obtain the records by subpoena from the insurance company. We have notified all of the individuals involved, however, that they are not the subject of the investigation or the target in the investigation. The targets are the attorneys and doctors, and so forth, involved in the fraudulent activity. So we have to say in this case we obtained them without the consent of the individual, and we did so with the grand jury subpoena.

Mr. PREYER. Mr. Keeney, do you have any comments?

Mr. KEENEY. No, I think that adequately sets forth the procedure, Mr. Chairman.

Mr. PREYER. Do you find that most doctors' and hospitals' record-keepers cooperate with requests for medical records? Isn't it fairly rare that you have to subpoena?

Mr. MULLEN. Yes; most cooperate. If it is a legitimate criminal investigation, we have had cooperation in almost all instances. I do know of isolated incidents where a facility or doctor will request that a subpoena or a release from the individual involved be obtained before making any information available. Mostly, they want some sort of release from the patient involved in the case.

Mr. PREYER. Is there anything in existing law which would prevent the Justice Department or the FBI from asking any doctor or hospital for the medical records of an individual?

Mr. KEENEY. I don't know of anything, Mr. Chairman.

Mr. PREYER. Does the Justice Department, Mr. Keeney, need the authority to ask for anyone's medical records at any time or for any purpose?

Mr. KEENEY. Well, Mr. Chairman, we have available the use of a grand jury subpoena if necessary, at the investigative stage.

Mr. MULLEN. If I might add, Mr. Chairman, normally we would have to have—in fact, I don't know of an instance where we have obtained a medical record without a subpoena or some form of a written agreement or release from the patient, even dealing internally with our own employees within the FBI. We had a case not long ago where something developed regarding the possible medical treatment, and we obtained a release from the employee prior to examining any medical record.

Mr. PREYER. Do you have any written regulations pertaining to obtaining medical records?

Mr. KEENEY. Not as such, Mr. Chairman. We have just the general guidance with respect to the grand jury's seeking of records where they are relevant to a grand jury inquiry.

Mr. PREYER. The administration's bill would allow virtually unlimited requests of medical records through the formal written request procedure. Mr. Keeney has suggested we should put the procedure into this bill. Is the Department opposed to any privacy law that restricts its ability to seek medical records?

Mr. KEENEY. No, sir, we are not, but the one thing that we feel that should be preserved is the right of a grand jury to obtain such records when they are needed in the course of their investigation. We think the safeguards that are traditionally provided by a grand jury are sufficient to protect the individual.

Now, on the formal written request, we would be in favor of giving the FBI the right to seek and the medical provider the right to be protected if he turned over records pursuant to such demand by the FBI. Unfortunately, that is not the answer to all of our problems, because I think Mr. Mullen can attest to the experience with a document that does not require the provider to give us the information. Our experience has not been that successful, for instance, under the Financial Privacy Act.

Mr. PREYER. One final question before I use up all of my time. As concern about privacy grows—and Lou Harris testified here a few weeks ago about the increasing concern about it in this country—do you think you will find more and more people refusing to turn over records without a subpoena; and, if so, what would that do to the Department's operations since you are able to obtain so many today through cooperative agreement?

Mr. KEENEY. Mr. Chairman, that has been the experience. There has been an increasing reluctance on the part of private citizens or companies to turn over documents to the FBI or other investigative agencies without some process that requires them to do so. That is particularly true—again I refer to the Financial Privacy Act—where cooperation is virtually disappearing. Even where we make the request, and the request is not complied with, we have to use a process that is compulsory.

Mr. MULLEN. I could add to that, Mr. Chairman. Mr. Keeney alluded to the Right to Financial Privacy Act, and we have found that some financial institutions are even declining to report crimes to us that have been committed. We have found, for instance, in one case a bank refusing to give us surveillance photographs of a bank robbery, feeling they were covered by the Privacy Act dealing with financial institutions. Agents have encountered significant difficulties in obtaining financial records with institutions just declining outright to honor the formal written request. In talking to some of the banking officials at conferences, and so forth, some will state, we know we are right, but there is a possibility of a lawsuit, so rather than take a chance, they are demanding a grand jury subpoena in each and every case.

Mr. KEENEY. Mr. Chairman, if I may add with respect to that, it is a problem we are running into increasingly, where there is any possible ambiguity in the statutory provision. With respect to the protection of custodians of the records, they are insisting upon a compulsory process. Even giving them the protection, so that they

can voluntarily provide the information or the record without being subject to suit, has to be made perfectly clear in any legislation or else it is of limited utility.

I think one example that the FBI has run into recently was when they had an embezzlement situation, and there was a hassle back and forth as to whether or not the bank was entitled under the Financial Privacy Act to make that information available to the FBI.

Mr. PREYER. Can the Justice Department and the FBI function effectively under the situation that exists today?

Mr. KEENEY. Well, Mr. Chairman, I hope that the committee in this type of legislation would give us authority for the clear-cut request to the FBI, which would protect the custodian. That is one step, but that is not the answer because that merely allows the custodian to give us the record. What we really need, Mr. Chairman, is to have an exception for the grand jury process. Then we can give them the process; they know they are protected; and they know they have to comply.

Mr. PREYER. Thank you, Mr. Keeney.

Mr. Kindness?

Mr. KINDNESS. Thank you, Mr. Chairman.

Mr. Keeney, I noted in your testimony that the Department needs medical record information to settle Tort Claims Act cases prior to the filing of the lawsuit. To clarify that, isn't that the sort of case in which the victim or the claimant could, and ordinarily would, in the interest of settlement provide a consent form?

Mr. KEENEY. Normally, yes, but it might be in the interest of the Department, too, particularly where smaller amounts are involved, if we had access to medical records which the individual may not be willing to provide.

Mr. KINDNESS. Could we reach the conclusion that is not a very significant overall factor in the number of cases involved; they would be rather limited, to begin with, I would suspect?

Mr. KEENEY. Mr. Lowell will answer the question.

Mr. LOWELL. If the question is whether there are many situations in which medical records are needed before Federal Rules of Civil Procedure could make them accessible, then it is probably right that they are scarce. It is not a large percentage, but there is a part that would be covered if the medical records bill occupied the entire scheme, the entire sphere. In other words, if the bill covers all access and has an exception for the Federal Rules of Civil Procedure or any litigation and then doesn't address those cases, small as they might be, in which access is needed prior to the Federal rules coming into play, then there would have been a segment left out of the coverage for which access would never be available.

It is a small area, but one which has to be dealt with in one way or another.

Mr. KEENEY. When we reach the litigative stage, section 130 would cover it.

Mr. KINDNESS. Those cases in which the consent of the claimant could not be obtained for this purpose, I would imagine are not very ripe for settlement, anyway. Isn't this the practical aspect?

Mr. LOWELL. I guess the provision we seek is to insure that discovery of medical records does not become a crucial aspect or a litigation technique. I guess the key here is that the bill doesn't provide a weapon, so to speak, for a delay in a case which ought to go to settlement as quickly as possible, but it is a small sphere, there is no question about it. Yet it shouldn't be one in which the act serves as a sword as opposed to a shield.

Mr. KINDNESS. Mr. Mullen, I am not entirely clear as to whether there is any existing authority under which the Bureau can compel disclosure of medical records information in an emergency situation. For example, in the case you described of the psychotic person who was holding the nurse at gunpoint.

Mr. MULLEN. No authority to compel compliance with the request, but normally in that situation we do have cooperation on the part of medical authorities.

Mr. KINDNESS. How long do the Department and the Bureau maintain individual identifiable medical records or information from medical records in the files of the Department or the Bureau, and what sort of safeguards do you have to prevent redisclosure of that information?

Mr. MULLEN. From the standpoint of the Bureau, we have our normal file destruction program. Certain files are destroyed within 5 years, others within 10 years, some we have to retain permanently; but the files are maintained on a confidential basis and not redisclosed to other agencies, except in an applicant's investigation for another agency it would be a part of the overall report.

Mr. KINDNESS. Then there is no special retention rule applicable to the medical records.

Mr. MULLEN. No, sir. They would pertain to our record system over all.

Mr. KEENEY. With respect to a document obtained by grand jury subpoena, the better practice and the required practice is that the documentation that is subpoenaed be returned at the conclusion of the proceeding. That might be very soon if the grand jury investigation is closed without prosecution or it may mean at the end of the trial if, in fact, the investigation results in indictment which goes to trial. All documentation subpoenaed by a grand jury should, in the normal process, be returned.

Mr. KINDNESS. It would be very seldom it would be returned without having been copied, isn't that true?

Mr. KEENEY. With a grand jury subpoena we would be bound by the rules of grand jury secrecy. If we completed the investigation and returned them to the custodian, there wouldn't be any copying. Now, there might be—during the course of the investigation—copying done for the purpose of the investigation, but all of that should be controlled. Normally I wouldn't see that being done.

Mr. KINDNESS. It would wind up in the investigative file, subject to the normal record retention.

Mr. KEENEY. To the extent that the grand jury examined records and leads went to the FBI. That would be in the possession of the FBI and in their record and subject to their records destruction policy, yes, sir.

Mr. KINDNESS. As to particular safeguards against redisclosure of information, there is, I take it, nothing that is a special procedure

or guideline at the present time except to the extent that you would, in your overall policies with respect to the files of the Department and the Bureau, restrict the use of those records and access to them; is that true?

Mr. KEENEY. Yes, sir; there is nothing special except to the extent we are dealing with a sensitive medical record; we would expect that good judgment would be used with respect to any dissemination, even beyond the normal grand jury restrictions.

Mr. KINDNESS. If, for example, upon an applicant's inquiry from another Federal department or agency, it was discovered that there was something nonrelevant in the medical record with respect to that applicant and the Department or Bureau had a file on that individual that contained something that was nonrelevant to the employment inquiry, how would the decision be made as to disclosure or nondisclosure of particular information, or at what level would it be made?

Mr. MULLEN. If it is not relevant to the ability to perform the duties in the position being sought, it would not be included in the investigative report. If it were a position such as special agent in the FBI, where you are required to perform certain physical tasks, it would be included in the report. But if it is not relevant to the position, it would not be included.

Mr. KINDNESS. How would that determination be made, and at what level?

Mr. MULLEN. It would be made at the investigatory level by the investigating agent and by the person supervising the investigation in the field office or possibly at headquarters.

Mr. KINDNESS. Would that be pursuant to any written guidelines that are available to them?

Mr. MULLEN. It would be pursuant to investigative guidelines, yes, but not guidelines pertaining to medical records.

Mr. KINDNESS. In the area of medicare and medicaid fraud, what is the frequency of activity in this area? Is there any way that you could describe the Department's activity in this area?

Mr. KEENEY. I can give you some figures with respect to the number of indictments that we have had in that area. But I might, as a prelude to that, indicate that, with the work of the Inspectors General, we anticipate there will be increased investigations prosecutions in both the medicare and medicaid area.

Now, having said that, I would emphasize that our experience to date is to the effect that 90 percent of the investigations and prosecutions relate to providers rather than beneficiaries. The figures that I have, Mr. Kindness—taking medicaid first—which we have broken out for the calendar year 1978, show 137 convictions in State proceedings for violations of the medicaid laws.

With respect to the Federal Government, the figures are not that firm, and I am afraid there may be a little bit of overlap, but I will give you what I have. For the calendar year 1978, the Postal Inspection Service investigated cases that resulted in 36 convictions. For the last quarter of 1978, the figure we have for the FBI is 30 convictions, and like the Postal Service, they are not broken down by medicare and medicaid; they are lumped together. With respect to HEW, we have 2 figures, 1 from the Office of Investigation, which shows a total of 31 for the calendar year 1978, and its

health care financial agency gives a figure of 39. I suspect there may be an overlap in those figures.

Mr. KINDNESS. In the case of the medicare/medicaid fraud situation, where the target of the investigation is a provider or providers, does it frequently occur that medical records used in the course of trials are used in such a manner as to disclose the identity of individual patients? What protections already exist in that area?

Mr. KEENEY. They could result in a disclosure of the names of individual patients. For instance, if you are dealing with an over-charge situation, the patient was administered the drug so many times, the doctor visited the patient so many times, the testimony of the patient might be put in to contrast or might contradict a claim being made by the medical provider.

Now, whether or not there could be any excision with respect to the record, I think that would be a matter for determination by the court. If the court determined, I don't see why it could not exclude the nature of the treatment that was being given, the nature of the illness for which the patient was receiving treatment. While the court, in its discretion, could keep that out of the trial record, I do not believe the court could keep that information from being provided to the defendant so that his counsel can adequately represent him.

Mr. KINDNESS. I take it that in these medicare and medicaid cases, it is very seldom the case that the investigation focuses from the beginning on the patient; is that correct?

Mr. KEENEY. That is correct, sir. As a matter of fact, with respect to individual patients, the beneficiaries of the program, we have agreements with the agency describing types of situations which we would not be interested in prosecuting and those involve certain minimal amounts of money, age of subject, whether or not reimbursement has been made, things like that. So the whole focus of the program is on providers rather than beneficiaries.

On the other hand, Mr. Kindness, occasionally when you are enforcing a program such as this, you have to go against an egregious beneficiary offender if you want to achieve what we are trying to achieve, namely, efficiency and nonabuse in the aid programs.

Mr. KINDNESS. Thank you, Mr. Chairman, I think I exceeded my time.

Mr. PREYER. Mr. Drinan?

Mr. DRINAN. Thank you, Mr. Chairman. I want to thank the witnesses, but I must say I am somewhat surprised at the further eroding of the bill that they are suggesting. I thought that all these principles had more or less the approbation of the Department of Justice.

Mr. Mullen, you have one statement on page 5, on which I would like some elaboration. You seek to point out alleged difficulties in the Financial Privacy Act of last year, and you state that "In many situations, therefore, crimes go unreported that would normally be reported to us for investigation."

Do you have some evidence for that? How many is many?

Mr. MULLEN. We do have some evidence of that. I do not have a copy of the document with me, Mr. Congressman. We solicited a

response from each of our 59 field offices, and we do have numbers of incidents where crimes have gone unreported and specific instances where they have gone unreported. I do not have a copy of that document with me.

Mr. DRINAN. You are suggesting that the rights of privacy which have been guaranteed by Federal law are undesirable and that you apparently want an amendment. Is that what you are saying?

Mr. MULLEN. Just to eliminate any confusion, some of the bank officials are unsure of the law and to be on the safe side, they are not reporting crimes and are requiring subpoenas in all instances, so just a clarification—

Mr. DRINAN. You are blaming it on the bankers. How would you amend the law if that is your intention?

Mr. MULLEN. I don't understand the question.

Mr. DRINAN. You say:

Financial institutions themselves are reluctant to furnish us with information and are often uncertain as to how much data they can provide in reporting a criminal offense.

The law is clear as laws can be that the right of privacy is guaranteed to the depositor.

Mr. MULLEN. Mr. Keeney addressed that topic in his statement.

Mr. KEENEY. Congressman, we are having problems relating to financial privacy, and we were just hoping that the committee in this bill would somehow make crystal clear what the obligations are of the provider so the experience we are having is not repeated. Because we have the legislation—again financial privacy—on the books, the people who are affected by it are construing it in the narrowest possible way, so that we are getting the absolute minimum cooperation, and we are forced to use—

Mr. DRINAN. They are complying with the law. You people come in and smear the law with scare tactics that all the criminals are going free because of privacy. I want documentation.

Mr. KEENEY. We are not saying that. We are saying that there are provisions in the Financial Privacy Act which allow, if we follow a certain procedure, for a financial institution to give us information. What we are saying is that the financial institution is concerned, and they make a narrow construction of the authority of the Department of Justice to get the information, and they are saying we are not going to voluntarily give it to you, even though the statute purports to protect us; we are going to insist on your using the compulsory process.

Mr. DRINAN. What is so terrible about that?

Mr. KEENEY. Mr. Drinan, if you give us the grand jury proceeding and except the grand jury subpoena from these strictures, we could live with it.

Mr. DRINAN. The Department of Justice lived with it last year. I don't recall an objection they had of that particular provision. You were in favor of it, and now you are opposed to it.

Mr. KEENEY. We are still in favor of it, Congressman Drinan, but what we are pointing out is that it does not satisfy all of our needs. Despite the fact that you tried to help us and give us this provision which allows the financial institution to cooperate with us, they are narrowly construing the statutory mandate, and they are requiring us to use the grand jury subpoena. We can do it. Let's hope

that you will allow us to continue to use the grand jury subpoena without the strictures that are set forth in Chairman Preyer's bill.

Mr. DRINAN. Mr. Mullen, I have problems with another recommendation. You propose that there be some exemption in emergency situations. That was not in the administration bill. That is not in Mr. Preyer's bill. I don't know how you define an emergency.

I am wondering if the Department of Justice recommends this exemption?

Mr. LOWELL. Congressman, let me clarify the point Mr. Mullen made. Both Chairman Preyer's bill and the administration bill have clauses to fit the needs of the FBI in phrases like "in which physical or property damage is threatened," in cases of this kind.

Mr. DRINAN. Is Mr. Mullen recommending something in the bill or not in the bill?

Mr. LOWELL. The chairman asked that we respond as specifically as possible to how we use records without regard to whether that access could continue under either bill.

One of our important needs is in the area of emergency situations. Both bills would cover that situation fairly adequately.

Mr. GELLMAN. Both the administration bill and the Preyer bill permit hospitals to make disclosures for emergency purposes, but neither bill requires them to do so. I believe the point that you were making is that I don't want to state your case for you—you need more than cooperation. You would like these disclosures to be required.

Mr. MULLEN. The facility would have to know that they can make it available in an emergency situation.

Mr. DRINAN. They may do that, but you are saying they ought to be required to do it and the FBI stands as the judge and jury of what is an emergency.

Is that what you are telling me?

Mr. MULLEN. I am not saying we should stand as a judge and jury.

Mr. DRINAN. If you go to court——

Mr. MULLEN. Should there be a misuse of the records, there is adequate penalty in the bill for that. So somebody has to make a decision in an emergency situation. I think a trained investigator in the FBI is as good a judge as anybody in that situation.

We recognize, Father Drinan, when there is a life or death situation and a decision has to be made, I am sure in 99 percent of the cases the hospital facility would make the information available, but there is always the chance that they may not. We have to have it very clear that they can and should make that information available in a serious emergency situation where there is a possible loss of life.

Mr. DRINAN. Mr. Keeney, I have problems on page 8. You apparently want a weakening of the law. You say that a related use of medical records is in connection with informants. I take it that before you accept a person as an informant you want to find out whether he is emotionally stable or addicted to drugs.

Are you suggesting that you would do this without the knowledge or consent of the prospective informant?

Mr. KEENEY. We would like to have the authority to do it without his knowledge or consent, yes, sir.

Mr. DRINAN. Why?

Mr. KEENEY. Because informants, Congressman Drinan, come to us in a variety of situations. We get into situations with informants where we are dealing in very sensitive areas and we would like to know as much as we can about the stability of the individual whom we are relying on.

Mr. DRINAN. Well, why don't you ask him to consent and just fill out the form?

Mr. KEENEY. That is one way to do it. With some informants you can do that without any risk. With an unevaluated informant it would be desirable for us to have medical records so we can ascertain his stability before we enter into any sort of relationship with him.

Mr. DRINAN. Well, you have problems enough with informants, it seems to me.

Mr. KEENEY. That is why we are trying to minimize them, Congressman Drinan. That is one of the points I am making here.

Mr. DRINAN. Well, Mr. Chairman, I have a lot of other questions as to why they want to qualify, to modify or compromise the bill even before it becomes law.

But I guess it goes back to the fact they want to make their job easier and they don't want to go through the ordinary processes of going to a Federal court in a routine procedure to get compulsory access.

The whole point of privacy is to say that this information is sometimes available, but we have to follow an orderly procedure and that the subject of records has to know about these things.

As I hear it, you want to get rid of that slight inconvenience to the Department of Justice and by so doing you obviously blunt the whole point of privacy, resulting in an unknown number of people having their records investigated without their knowledge or consent.

The whole point of privacy, to repeat, is that people should have their records available, but they should know that they are available.

I yield back the balance of my time.

Mr. KEENEY. If I may just comment on that, we are not dealing with—as you have described it, Congressman Drinan—a convenience or an inconvenience to the Department of Justice.

You are overlooking a major factor here and that is the inconvenience and the burden that is being placed on an already overburdened Federal judiciary because you are asking the courts to make individual judgments in situations where they are not being called upon to do that now.

We feel that the privacy interest of the individual patient can be sufficiently protected by utilization of the grand jury subpoena.

Mr. PREYER. Thank you.

Mr. Erlernborn?

Mr. ERLERNBORN. Thank you, Mr. Chairman.

Mr. Keeney, the thrust of your testimony, I must say, is somewhat familiar. Very often we have witnesses who endorse legislation in general and then suggest exemptions for their particular activities to the point where you wonder whether the legislation is really worthwhile.

It is good if it applies to somebody else, but not to them.

Would you care to comment on that?

Mr. KEENEY. Well, Mr. Erlenborn, what we are trying to do is to suggest appropriate safeguards. We are not really focusing on most of the bill. We are in general agreement with the privacy of medical records.

What we are saying is that in an era when the focus of the Congress and the citizenry in general is on efficiency of Government programs—and we are working now with the 14 Inspectors General trying to minimize the fraud and abuse in these programs—we are saying that in our view a compromise can be struck by relying on the secrecy of the grand jury proceeding to protect the individual patient rather than going into a system where the grand jury proceedings would not be available except by having what the Supreme Court calls minitrials, et cetera, before the court, with respect to the balancing test as to whether or not the Government's interest, our interest, all of our interests in getting these records is outweighed by the infringement on the individual's privacy.

We think if you preserve, as has been preserved in the financial privacy legislation, the right of an unfettered grand jury subpoena, that both objectives can be achieved.

Mr. ERLBORN. Let me make it understood that my criticism of your testimony probably stems from a different outlook on this legislation than that of my colleague, Father Drinan.

I rather like the suggestions you have made as to exceptions and exemptions since I think they are in the best interest of the administration of justice which I think is a very important one.

My question is, Why do we need this legislation in the first place? Are you aware of any widespread egregious abuse of medical privacy that requires the enacting of Federal legislation which then would require the exemptions of the justice administration to be served?

Mr. KEENEY. Mr. Erlenborn, I am aware of no abuse.

Mr. ERLBORN. That is the basic question. I am not certain that the quality of the Congress should be judged by the number of bills that are enacted, but rather by the quality of legislation.

My own philosophy says, don't pass legislation unless it is really needed. If there is no widespread abuse that you are familiar with, why would you be led to believe that we need legislation such as this?

Mr. KEENEY. Mr. Chairman, we are responding, as we did in the financial privacy area, to legislation that was proposed and we are trying to come up with a compromise that would protect the perceived problems, protect the interests that are being perceived by Members of Congress, and at the same time enable us to carry out our congressionally mandated function of seeing that prosecutions are effectively and efficiently carried out.

Mr. ERLBORN. I take it what you are saying, then, is if in its wisdom the Congress should enact legislation, these safeguards should be incorporated so that the administration of justice may be protected.

Mr. KEENEY. Yes, sir.

Mr. ERLNBORN. Let's assume that your answer to my question about widespread abuse is that you are familiar with widespread abuse and legislation is necessary.

Can you think of any good and valid reason why legislation of that nature should be at the Federal rather than the State level?

Mr. KEENEY. If there is an abuse at the Federal level, there would have to be Federal legislation, Mr. Erlenborn.

Mr. ERLNBORN. Well, what if the abuse were at the State level?

Mr. KEENEY. Medicaid is primarily a State-administered program; abuse in that area could be addressed by the individual States. But since there is heavy congressional funding, if there is abuse, particularly if it is widespread, I would assume that Congress would have a legitimate interest in trying to prevent that abuse.

Mr. ERLNBORN. I have not yet been persuaded that every problem that cries for a solution necessarily needs Federal legislation. Let's look at some Federal crimes such as interstate transportation of stolen property, a motor vehicle. We don't have Federal registration of motor vehicles. We don't have Federal licensing of drivers. We seem to be able, as a confederation of States, to live with State licensing of a whole bunch of things, not only automobiles and drivers but physicians, hairdressers, lawyers. There are many things that have been done at the State level.

Do you really believe there is a compelling need for Federal legislation in this area as opposed to licensing of drivers and registration of automobiles?

Mr. KEENEY. Mr. Erlenborn, I don't feel a compelling need, but there are people whose judgment I respect who feel that there is a need in this area and we in the law enforcement community are trying to suggest ways in which the problem that is perceived can be handled without unduly hampering law enforcement efforts.

Mr. ERLNBORN. One last line of inquiry.

You will probably remember maybe a year ago or more, the Better Government Association in the city of Chicago, together with one of the newspapers, I don't recall now which one, engaged in an investigation of medicare and medicaid fraud and had a whole series of articles which I think has led to a good deal of law enforcement activity in the Chicago land area.

Would you say that that type of investigation by private, nonlaw enforcement agencies is helpful?

Mr. KEENEY. Yes, sir, I would. I might say the Better Business Bureau group did a great job in that respect. Unfortunately, we don't have enough of those, Mr. Erlenborn, throughout the country, but they were very effective. They dramatized a situation and focused the attention of both State and Federal agencies on the problem.

Mr. ERLNBORN. If this legislation were in place, even with the amendments that you suggest to protect law enforcement agencies, would that not foreclose this type of investigation by citizens associations and newspapers and make it impossible for that scenario of exposure and then law enforcement activities to be repeated?

Mr. KEENEY. I think there is some possibility that this type of legislation would inhibit the private as distinguished from the State investigative effort. I am hesitating a little, Mr. Erlenborn,

because as I recall that investigation, it was primarily an undercover operation. I don't know the extent to which they utilized or sought to utilize medical records.

Mr. ERLNBORN. Thank you very much.

Thank you, Mr. Chairman.

Mr. PREYER. Thank you. We appreciate your testimony very much, gentlemen, and we will look forward to further information from you on the Financial Privacy Act experience particularly. We may have some further questions as we go down the road.

Thank you very much.

[Additional correspondence follows:]



United States Department of Justice

DEPUTY ASSISTANT ATTORNEY GENERAL

CRIMINAL DIVISION
WASHINGTON 20530

JUL 16 1979

Honorable Richardson Preyer
Chairman
Subcommittee on Government Information
and Individual Rights
Committee on Government Operations
U.S. House of Representatives
Washington, D.C. 20515

Dear Mr. Preyer:

Pursuant to the opportunity you graciously extended to the Department of Justice at the conclusion of my July 9, 1979, testimony regarding federal medical records privacy legislation, I am writing to document and supplement the Department's comments regarding H.R. 2979.

To confirm my July 9 remarks, the Department of Justice must oppose those provisions of H.R. 2979 which would depart from the Financial Privacy Act by placing restrictions upon federal grand jury subpoenas. As you know, the federal grand jury is a constitutionally authorized and required mechanism for investigating and bringing felony charges in the federal system. So important is it to safeguard this process from litigious interruption and delay that the Supreme Court of the United States has repeatedly held that the grand jury process should not be hampered by minitrials, evidentiary hearings, and other disruptive proceedings. In United States v. Calandra, 414 U.S. 338 (1974), the Supreme Court held that even the victim of an allegedly unconstitutional search and seizure, who would clearly have standing at trial to challenge the introduction of the seized evidence, would, nevertheless, not be heard to protest its introduction and use before the grand jury. Because the statutory rights to prenotification and standing that would be created by a statute cannot claim to rest on greater privacy grounds than a claim of unconstitutional search and seizure, it would be anomalous and would produce inconsistent results if federal grand jury subpoenas were subject to the requirements of a new medical records privacy law.

In addition to the unique legal and constitutional status which the federal grand jury occupies, it is protected by rules insuring the secrecy of its proceedings. Expanded notice and challenge rights in the grand jury context could seriously jeopardize the rule of secrecy, and, in so doing, violate the privacy rights of individuals being investigated. Further, federal grand juries are already subject to the supervision of the United States District Courts.

The threat to grand jury secrecy is especially pronounced in the medical records area. In a Medicare fraud investigation, for example, it may be necessary to review records pertaining to numerous patients to determine whether a physician in fact committed the fraudulent acts being investigated. If a medical care facility refuses Departmental investigators access to medical records pursuant to Sections 125 or 129, both of which are voluntary access mechanisms, we would have no choice but to proceed by grand jury subpoena. And if all these patients are given notice of the grand jury subpoena and an opportunity to challenge the subpoena in court, there is substantial likelihood that the purpose of the investigation will become public and perhaps even be reported in the news media. Such publicity would be extremely detrimental to the physician involved and would defeat one of the most important purposes of grand jury secrecy.

A second major concern with H.R. 2979 is the showing required to prevail after a challenge to access is filed or to secure a court order delaying notice. Specifically, the bill would require "reasonable cause" to believe the records are relevant to the investigation and a finding that "the government authority's need for the record in the inquiry outweighs the individual's privacy interest." Both of these requirements seem inappropriate given the fact that they must be met during the investigatory stage of a proceeding. In this regard, "reasonable cause" is sometimes read as being equivalent to "probable cause" which is the standard of proof that must be shown to obtain an indictment at the conclusion of an investigation. At the pre-indictment stage, therefore, the information available to the government is necessarily often less than probable cause. We would urge the Subcommittee, therefore, that a standard no higher than "reason to believe," "reasonable belief" or "reasonable grounds to believe" be imposed by any medical records privacy bill. As the Subcommittee is aware, the Financial Privacy Act uses the term "reason to believe."

We further oppose the notion of the balancing test requiring the court to weigh government need for the record against the individual's privacy right. Again, at the investigatory stage of a proceeding the government is not in possession of all the facts necessary to establish its "need" for a record; in most cases, it can only show relevance to a legitimate law enforcement inquiry. Under H.R. 2979, however, the government may meet its burden of proving relevance but still be denied access. Such a result seems unwarranted.

Further, the balancing test poses enormous practical difficulties. First, the scope of the balancing inquiry is unclear. It might include the type of investigation in connection with which the record is sought with greater need ascribed to felony than to misdemeanor investigations. The need could be considered to vary depending upon the seriousness of the felony or misdemeanor offense with more weight accorded an investigation into an offense which carries a punishment of ten years' imprisonment than to one punishable by five years' imprisonment. The number of counts being considered may be determined to make a difference. The past criminal convictions of the suspected offender could be taken into account. On the other side of the balance, does every person have an equal privacy interest in his or her medical records regardless of the information they contain or does an individual's privacy interest vary depending upon the sensitivity of the information in the medical record (i.e., does A have greater privacy rights in his medical records than does B because A's records reflect treatment for a social disease while B's records reflect an appendectomy)?

Even if painstakingly re-written, the balancing test would impose a substantial burden upon federal courts which would, in most cases, find it necessary to review both the medical records sought and a detailed statement of the government's case in order to determine whether the need for the medical records outweighs privacy interests. No such test is used in the Financial Privacy Act and the Department of Justice believes it should be deleted from this bill. We believe that a person's right to privacy in records is the right to require that the government be able to demonstrate the legitimacy of its investigation and the relevancy of the records thereto. Once such a showing has been made, the government should be permitted access.

A third point is the need for an exception, similar to Sec. 105(b)(18) of H.R. 3444, to cover medical records maintained by the United States Bureau of Prisons. It should be noted that the status of a person incarcerated in a federal penitentiary is quite different from that of other citizens. Prisoners have many restrictions on their rights as the result of penal laws and regulations. Further, a prisoner's medical records are very often kept together with all other penal records as the institution is responsible for overseeing virtually every aspect of an inmate's life. The Subcommittee should also be aware that the Department is currently developing standards for increased access by prisoners to records relating to them.

There are special problems in restricting law enforcement access to prison records. In investigating crimes committed within the institution, for example, it is very unusual for any inmate to cooperate with the investigation. Documents, therefore, are more important in such investigations than in normal cases. Further, there is a clear need for prison officials to control drug use by inmates; medical records are important in identifying potential drug problems and in taking action to close off the flow of drugs into the facility. In short, we believe that application of the bill to medical records of federal prison facilities is inappropriate.

In addition to the above general observations discussed in my oral remarks of July 9, we offer the following specific comments regarding H.R. 2979.

1. Section 102(a) should refer to Sec. 127(a) to avoid misconstruction of Sec. 102(a) as superseding state laws requiring reporting to law enforcement authorities of medical information evidencing child abuse and other offenses.

2. Section 103 of the bill relating to rights of minors and incompetents should be carefully reviewed as it would appear to reduce the ability of law enforcement authorities to protect minors and incompetents from fraud, theft, physical abuse and other crimes perpetrated by corrupt trustees, guardians and conservators.

3. Section 114(3) apparently gives medical facilities authority to censor medical records sought by law enforcement authorities even though law enforcement officials have complied with all applicable provisions of the bill. While we appreciate the desire to protect all but relevant portions of medical records, it is highly inadvisable to permit any private authority -- which may be the subject of the investigation in connection with which the records are sought -- to determine which parts of a medical record are relevant to an investigation and which are not. The Financial Privacy Act contains no such provision.

4. Subsection 123(1) should be modified to permit disclosure to law enforcement authorities without regard to whether the individual objects. Obviously, those individuals about whom law enforcement authorities are most likely to inquire will routinely object to disclosure. Further, the amount of information which may be disclosed under this section is so limited that it is difficult to understand how any individual could legitimately object to its disclosure to law enforcement officials. Finally, Sec. 123 should not be written in such a way that it may lead medical facilities to refuse compliance with Sec. 129 which permits disclosure of the presence of a fugitive at the facility.

5. Section 125, "Audits and Investigations," is unclear in its relation to Section 129, "Law Enforcement." It is ambiguous whether an audit of a medical facility for suspected fraud or abuse in connection with federal program funds would be covered by Sec. 125 or Sec. 129(a)(1)(A). This is especially true if an investigation is conducted under the supervision of a task force made up of an Inspector General, FBI agents, and a U.S. Attorney. Under either section, a facility could apparently decline to permit review of medical records. Moreover, as in Sec. 114, the medical facility is authorized to censor records being reviewed by examiners. Finally, the use restriction of Sec. 125(b)(4) could be read as prohibiting transfer of identifiable medical records evidencing fraud or other crime to the Department of Justice for prosecution. Because such a transfer is for a purpose consistent with and arising from the purpose for which the records were initially examined, such a restriction is inappropriate and unnecessary.

6. Section 127 permits medical facilities to disclose records as required by state or federal law. This section should be revised, however, to incorporate language similar to Sec. 105(b)(6)(A) of H.R. 3444 so that law enforcement authorities can promptly investigate offenses reported pursuant to this section.

7. Section 129 authorizing law enforcement access is entirely voluntary and may be frustrated by refusal of the medical facility to permit access. The relation between this section and Sec. 131 is, therefore, not clear. Further, Sec. 129(a)(1)(A) is limited to investigations directed at someone other than individuals who are the subjects of the records being sought. Yet patients are sometimes involved in program fraud. More important, it is often impossible to know who is involved in a scheme until after medical records are reviewed. In addition, Sec. 129(a)(2) could be read as requiring a separate certification for every record examined and would constitute a substantial paperwork burden in large-scale investigations. Finally, like Sec. 125, this section also contains an unwarranted re-disclosure restriction limiting use of records needed for criminal prosecutions.

8. Section 130(b) again restricts re-disclosure despite the fact that the use of records obtained under Sec. 130 in connection with criminal prosecution is consistent with and arises from the initial use.

9. Section 131 should provide a Formal Written Request access mechanism for agencies such as the FBI which do not have administrative process. It is the view of the Department of Justice that the Formal Written Request as established by the Financial Privacy Act provides abundant protections for individual privacy without needlessly disrupting the operations of the numerous federal agencies which may occasionally require access to medical records. If no Formal Written Request procedure is established, the Committee should provide agencies with administrative process.

10. Section 141(a) should be re-written to use a "reason to believe" or similar standard and to eliminate the balancing test as discussed earlier.

11. Section 141(b) should be revised to conform to The Financial Privacy Act which permits 90 days rather than 30 days between execution of a search warrant and notice. Further, this subsection, as written, conditions the issuance of a search warrant upon the giving of post-notice, an impossibility.

12. Sec. 141(c)(1) should, in addition to delaying the government's obligation to give notice, prohibit the medical care facility from notifying patients of access during the period of court-ordered delay. The Financial Privacy Act provides for such protective orders.

13. Sec. 141(c)(2) again uses the "reasonable cause" standard and the balancing test upon which we have previously commented.

14. Sec. 142 relating to venue of challenge suits must be clarified to provide that suits challenging federal process may be brought only in federal courts. In addition, the section should be revised to limit suits challenging judicial subpoenas to the district from which such process issued as does the Financial Privacy Act. Further, the burden which the patient must meet should be specified as is done in the Financial Privacy Act.

Also, an in camera review procedure should be provided, as is set out in the Financial Privacy Act, to prevent abuse of the challenge provision to obtain discovery of the government's criminal case; the Federal Rules of Criminal Procedure afford adequate discovery opportunities at an appropriate time. Finally any grant of standing to challenge grand jury subpoenas would require special venue provisions to insure that suit could only be brought in the district in which the grand jury sits. The Subcommittee should also be aware that challenge actions, unless specifically designated as miscellaneous proceedings, will be treated as regular civil actions by the Administrative Office of the United States Courts; the filing fee for civil actions is currently \$15.00 and will advance to \$60.00 as of October 1, 1979, whereas the filing fee for miscellaneous actions is \$1.00.

15. Sec. 142(b)(1) requires courts to give patients two opportunities to challenge government access to records. The Financial Privacy Act provides for only one motion to quash and one affidavit, leaving it to the discretion of the court as to whether additional pleadings are necessary to decide the issue. If the patient's initial filing was without merit and if the government's response clearly establishes that it is entitled to access, the court should not be required by statute to entertain further pleadings.

16. Sec. 142(d)(1) is worded in a prejudicial manner to imply that courts should routinely grant motions to quash; it also repeats the balancing test previously discussed.

17. Sec. 141(d)(1,2) should parallel the Financial Privacy Act which specifies that a minor or technical violation of the Act does not justify quashing government process. Further, awards of attorneys fees should be limited to civil damage actions as is the case under the Financial Privacy Act.

18. Section 143 sets out agency reporting requirements that are based on but inconsistent with the Financial Privacy Act. The Department favors the approach proposed in H.R. 3444 whereby records are maintained but are reported only upon request.

19. Section 153, while patterned on the Financial Privacy Act, does not incorporate the principle of the proposed Federal Tort Claims Act Amendments restricting civil suits against the federal government to actions against agencies rather than individual federal employees.

Revising Sec. 153 to make it consistent with Federal Tort Claims Act Amendments would provide plaintiffs with a solvent defendant, the United States, and would avoid conflict of interest situations which now sometimes require the Department of Justice to employ attorneys from the private bar to represent federal employees.

20. The bill should incorporate a provision similar to §1119 of the Financial Privacy Act (12 U.S.C. §3419) tolling applicable statutes of limitations during the pendency of a motion to quash. Failure to provide such a tolling section would permit individuals to avoid criminal prosecution by stalling an investigation until the statute of limitations on the offense has run.

Finally, as we indicated at the hearing, the Department of Justice and other federal agencies are presently evaluating our experience under the Right To Financial Privacy Act of 1978 which went into effect on March 10 of this year. Because both H.R. 2979 and H.R. 3444 are patterned on the Financial Privacy Act, we will, of course, provide the Subcommittee with a complete report on experience under that Act.

Again, we deeply appreciate your permitting us to proceed in this manner and will be pleased to testify further before the Subcommittee at your convenience if desired. In the meantime, I hope the Subcommittee and its staff will not hesitate to call on the Department at any time as we want to lend every possible assistance to you in your important work. The Office of Management and Budget advises that there is no objection to the submission of these views from the standpoint of the Administration's program.

Sincerely, .7



John C. Keeney
Deputy Assistant Attorney General
Criminal Division

Mr. PREYER. Our next witness is Mr. Richard Lowe, Deputy Inspector General of the Department of Health, Education, and Welfare.

It is good to have you with us today, Mr. Lowe.

STATEMENT OF RICHARD LOWE, DEPUTY INSPECTOR GENERAL, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

Mr. LOWE. Good morning, Mr. Chairman. I would like to have members of my staff, Miss Callahan from the Office of General Counsel, Mr. Richard Campbell, and Mr. Frederick Lehrer.

Mr. PREYER. It is good to have you all here today. Your statement will be made a part of the record. You may proceed in whatever fashion you see fit.

Mr. LOWE. Thank you, Mr. Chairman, members of the committee. Thank you for your invitation to testify today on your proposed medical privacy legislation.

The Office of Inspector General appreciates the opportunity to discuss the uses we make of medical records data and the possible impact of this legislation on our ability to detect and prevent fraud, abuse, and waste in HEW programs.

We fully recognize that medical records often contain the most sensitive personal information, information which should be kept as confidential as possible. The Office of Inspector General endorses the concept of Federal legislation to protect the privacy of individual medical records.

However, as you know, the Congress mandated that the Inspector General insure, among other things, the honest, efficient and economic administration of federally funded health programs. This objective requires us to inspect certain records of medical care providers including, in some instances, patient medical records where the Federal Government has paid in whole or in part for the health care services.

Our HEW Audit Agency, a part of the Inspector General's Office, performs few audits of medical care providers directly. Audits of providers of services under the medicaid program are primarily conducted by State agencies.

Likewise, audits of providers of medicare services are conducted by medicare fiscal agents, that is, intermediaries and carriers. We in turn have the responsibility of auditing the State agencies and fiscal agents.

HEW auditors also respond to special requests for audits, made primarily when questions arise concerning a particular provider of services. If the financial operations of the provider are at issue, the audit would most likely be limited to a review of financial records.

In any case, we do not automatically review patients medical records. It is also not our standard policy to examine the entire medical record system.

For the relatively few audits requiring review of selected patient medical records, the examination is necessary in order to verify that the services billed by a medicare or medicaid provider were warranted and were actually performed.

We might also want to look at medical records where a joint effort is made by auditors and investigators, or where an audit reveals facts which justify referral for investigation. Documenta-

tion of questionable activities may require that more specific information be collected. This could include data from patient medical records.

It is our policy that audit reports, whether internal or public, contain no personal information identifiable with particular individuals. Audit work papers are not routinely made available outside the HEW Audit Agency.

Information referred for investigation and prosecution is almost exclusively limited to questionable activities on the part of persons other than the patient.

I know of no case in which medical information was referred for other law enforcement purposes where the patient was the target of the investigation.

While the HEW Audit Agency performs a relatively small number of the medicare/medicaid provider audits, I would like to emphasize that the audits we do conduct are of great importance to the two programs. In our opinion, the ability to conduct special audits acts as a major deterrent to fraud and abuse.

Furthermore, the ability of State agencies and medicare fiscal agents to have access to all records pertinent to their audits of health providers is critical to the administration of federally funded health programs. I, therefore, urge the committee to give representatives of these organizations the opportunity to discuss this bill with you.

Turning to another part of the Inspector General's office, the Office of Investigations needs access to medical records to investigate allegations of criminal wrongdoing on the part of health care providers. Our investigators must be able to inspect medical records of patients for a number of reasons.

First and foremost is the absolute need to verify specific information on a physician billing under medicare or medicaid programs. Without access to patients' medical records, investigation into possibly fraudulent physician billings would be impossible.

For example, where a patient has been hospitalized and a physician has also billed for an office visit during the same period of time, dates and other notations in the medical records must be compared to determine whether there was double billing.

In addition, investigations into sophisticated reimbursement schemes, which manipulate patient days so as to increase medicare and medicaid reimbursement, can only be conducted by examining patient records.

Access to information obtained in the course of an investigation is strictly limited to employees working on the case or other employees who have an absolute need for the records. All access is carefully monitored by the Office of Investigation.

As a rule, disclosure outside our office is restricted to the same purpose for which the records were originally obtained. This would include, for example, disclosure to the Department of Justice for prosecution, to State agencies and the Health Care Financing Administration for abuse investigations and administrative actions, and, on occasion, to the FBI for further investigation.

It is also our policy to cooperate with other law enforcement agencies where they need information maintained in our files.

However, such requests are rare and would almost always be related to similar health program investigations.

As a third general area of activity, we have conducted certain special projects in order to learn more about the extent of fraud and abuse in the medicaid program and how to improve our detection ability. The projects consisted of analysis of medicaid claim forms submitted to State agencies for payment.

The purpose of the analysis was to identify cases where services provided greatly exceeded reasonable parameters. Certain cases were then reviewed in great depth to determine the reasons for the high or irregular pattern of services. In the course of the review it was sometimes necessary to obtain additional documentation from patient records.

However, we did not seek access to patient records unless evidence indicated fraud or abuse by the provider. We believe that these types of projects are essential to an effective antifraud and antiabuse program. A basic step in any effective program is the careful analysis of claims data furnished to the Government.

In light of the outline I've given you of our activities and responsibilities, I think you can understand how essential it is for us to retain the right of access to patient medical records. We have invoked our authority sparingly in the past and will continue to exercise it with discretion in the future.

H.R. 2979 in its present form could hinder the performance of our duties in several ways. The requirement under part D to give notice and an opportunity to challenge to any individual whose records are subpoenaed could be extremely onerous if taken to apply to all the other sections of the bill permitting Government access.

We believe it is likely that medical providers, put on notice by this legislation that they may disclose patient records only in certain limited circumstances, will react very cautiously to any request for information.

Based on the reaction of other institutions with similar responsibilities under parallel privacy protection statutes—I am thinking particularly of the restrictions on disclosure of financial information imposed by the Right of Financial Privacy Act of 1978—providers of medical services are likely to refuse access to patient records without compulsory legal process in order to shield themselves from any possible liability.

In that event, which we consider virtually inevitable, we would have to use our subpoena power to reach the records we needed. If, in order to serve the subpoena, we had to observe the notice and challenge requirements specified in part D for every individual patient, even though the patient himself was not the focus of our inquiry, the process of audit and investigation would be substantially impeded.

The delay and expense of notifying each patient whose records are sought as part of a test sample, not to mention the unnecessary apprehension it would create in those whose records were subpoenaed, would cut drastically into the effective performance of our mission.

Where the auditee or the target of an investigation is the provider of medical services rather than the recipient, we believe that it is vital that the legislation make clear that notice and opportunity

to challenge need not and should not be given to individual patients unless they are targets themselves, an occurrence which, as I have said, is extremely rare.

I would also like to comment briefly on the redisclosure provisions in the bill.

Redisclosure restrictions are of great concern to us. As I have explained, it is our policy to cooperate with legitimate law enforcement investigations, particularly in the health care field. We firmly believe that it is our responsibility to assure that evidence of wrongdoing in our possession is thoroughly investigated, and referred for prosecution when warranted.

In light of this, we are greatly troubled by the restrictions on reuse and redisclosure in section 125 of the bill. This section, which governs access to records for audit and evaluation purposes, limits redisclosure of records to four narrowly defined situations. It does not provide for disclosure for law enforcement purposes even where the records are needed for provider-fraud investigations.

At a minimum, we believe that redisclosure should be at least as permissive as section 129 of the bill, which permits redisclosure on the same basis as the original disclosure.

We have some difficulties with other sections of the bill. Since these sections are likely to have considerably less impact on our operations, I will not take the subcommittee's time to address them today. However, I would appreciate the opportunity to have my staff discuss these additional concerns with your staff in the near future.

For the record, I would also like to point out to the committee that the administration has sent to the Congress its own proposal pertaining to the privacy of medical records. The concerns that I expressed in regard to H.R. 2979 have, we believe, been adequately addressed in the administration's bill.

Again, I would like to thank you for this opportunity to comment on the proposed bill.

Mr. PREYER. Thank you very much, Mr. Lowe. I think you have pointed out some problems in the bill which were not foreseen at the time the bill was drafted. I think you have made some valid points that we can attempt to work out.

Mr. Drinan?

Mr. DRINAN. Thank you, Mr. Chairman.

I want to thank Mr. Lowe. I have not met an Inspector General before. It is good to have a Deputy Inspector General appear before this subcommittee.

I wonder if you would have any reflections on what the Department of Justice and the FBI said a few moments ago?

Mr. LOWE. Well, our interests sometimes are not the same, but most often they are comparable. After all, when the Inspector General prepares a case for investigation, we turn the fruits of our labor to the Department of Justice for action.

Many of the concerns that they have expressed, frankly, we share and we do agree with. I suppose the major difference between our concerns and perhaps those of the Department of Justice is that our primary targets are providers and our great concern is that when we pursue investigations with respect to individual pro-

viders, we are not speaking of one individual in terms of the accumulation of the evidence that is necessary to make a case.

One provider may have hundreds of patients whose records contain the information which we need to make the case against one provider. So our concerns to some extent are less than the Department of Justice because the Department of Justice also pursues investigations with respect to individual patients themselves or recipients, although to a lesser extent.

Mr. DRINAN. Do you ever use undercover agents in hospitals to help collect information about illegal practices?

Mr. LOWE. We don't. However, we have a very close partnership with the States in their investigations into nursing homes and hospital investigations.

As a matter of fact, the Inspector General's office has now assumed the oversight responsibility of the section 17 units which have recently been created.

In many instances they will use the undercover capacity to determine fraud and abuse within hospitals and nursing homes.

Mr. DRINAN. Thank you.

One last question: I don't know whether you have had the occasion to read Dr. Wolfe's statement, one of our next witnesses. I wonder if you would have any comments on what he says, especially where he says toward the end that he believes that the particular section which provides for disclosure of patient records to court authorities for use in investigation of fraud, should be made so strict as to require the deletion of all patient identifiers?

Mr. LOWE. I read that one paragraph, Father Drinan. I can't agree with it in terms of its sweeping scope.

For example, if we make a case against a particular provider, that provider, if he is prosecuted, is of necessity going to have the absolute right to know the source of the evidence against him, and if we produce the evidence without identifying the individual so that the court can make a determination as to whether that name can be deleted—I do not believe, would be accepted by the court.

I agree with the safeguard that was mentioned in the previous testimony, that is, the courts can determine whether or not the identity of a particular patient is necessary in the prosecution or the defense of a case.

I frankly believe that in most instances these names could be deleted or at least sealed in the record. But the court is going to have to have the opportunity to make that determination.

Mr. DRINAN. I thank you very much. I thank you for your testimony. I yield back the balance of my time.

Mr. PREYER. Mr. Erlenborn?

Mr. ERLBORN. Thank you.

Mr. Lowe, in listening to your testimony and reading it, I do not consider this to be a ringing endorsement of the legislation before us.

Has the Inspector General taken any position pro or con on the basic legislation?

Mr. LOWE. Well, we have trouble with the bill and, frankly, we have trouble even with the administration bill. I must say that, as I mentioned before, our primary concerns, due to limited staff and resources, is toward provider abuses.

First of all, we believe that the magnitude of the problem is much more widespread on the provider level in terms of volume and in terms of the amount of money that these abuses represent. But we can live with portions of the bill.

Frankly, we would want those concerns that we have expressed addressed and we hope, resolved in our favor. It is a thin line, Congressman, to have an opinion with respect to privacy, the individual's privacy rights.

I think most, if not all, of us adhere to that principle and would like safeguards along those lines.

On the other hand, very often in terms of addressing a problem, sometimes you create larger problems by trying to solve the one problem. I think the concerns of law enforcement are legitimate.

The criminal justice system is terribly overburdened and the effects of some of the provisions in this legislation would impact drastically upon the volume of cases in the presently overloaded courts today.

Mr. ERLNBORN. In your experience do you believe there is now widespread abuse relative to the privacy of medical records?

Mr. LOWE. I don't know personally of widespread abuse. I am sure that there are examples of abuse. But I cannot state to this committee that I know of widespread abuse with respect to patient medical records.

Mr. ERLNBORN. We had one of the pollsters here who testified relative to this legislation. His conclusion is that the public believes there is abuse and he either was not aware that there really was or didn't believe there was widespread abuse, but I think his conclusion was that we should legislate to address public concerns.

Mr. LOWE. I have read Mr. Harris' conclusions.

Mr. ERLNBORN. I personally believe we ought to be legislating in the real world, addressing real problems, rather than trying to engage in public relations efforts to address what may be unjustified, unwarranted public conclusions.

Mr. LOWE. I think I agree with you.

Mr. ERLNBORN. Thank you very much.

Thank you, Mr. Chairman.

Mr. PREYER. Thank you, Mr. Erlenborn.

Mr. Lowe, with respect to several of your concerns on the bill, I think we can all agree that when a medical record is used for the purpose of an audit, the patient's privacy interest is relatively small compared to the interest of keeping proper physical records and proper administrative controls.

You make the point on page 6 that, if you had to notify each patient whose records are being sought as part of a test sample, it could cause a great deal of delay.

Well, I can see how that would be a valid point and I think that is one we could address. But one thing I think would be of great concern to the patient in the audit situation is the disclosure or reuse of information.

Even if you believe that in an audit the privacy concerns are not as high as in some other areas, I think you would agree that the redisclosure and the reuse of that information is a very important area.

You make the point on the last page of your statement that your objection to the redisclosure section seems to be that it applies only to four narrowly defined situations, and that it doesn't provide for disclosure for law enforcement purposes even where the records are needed for provider fraud investigation.

Is that your main objection to the redisclosure provision in the bill?

Mr. LOWE. Yes, Mr. Chairman.

Mr. PREYER. If we took care of that provision, would you have any other objection to the redisclosure provision?

Mr. LOWE. Mr. Chairman, we would not have any major objections to the redisclosure provisions if they were modified as you stated.

One of the problems is that as we see it with respect to comparing 125, that is the audit section, with 129, that 129 permits redisclosure for the purpose of the original intent of getting the information, whereas there is no such provision in the audit section.

I think the thing that is overlooked very often is that the Audit Agency and the Investigations Agency is within the Inspector General's Office. They are not severable, distinct agencies any longer. They makeup the Inspector General's Office.

If the Audit Agency in the course of an audit comes across information evidencing criminal wrongdoing, the provision of 125 seems to suggest that they could not even turn that information over to a very significant partner within the same agency. That is the Office of Investigations.

It is the Inspector General's mandate to investigate fraud and corruption. As I said, the Audit Agency is part of the Inspector General.

Mr. PREYER. Well, I can understand your point on that. I think we can resolve that.

Let me ask you this: Would the Inspector General object to a provision that explicitly prohibited all collateral uses of medical information obtained during an audit or fraud investigation?

I gather from your testimony that you in effect are saying that you don't do that anyway, that you are careful in collateral uses of this testimony.

Would you object to an explicit provision on that?

Mr. LOWE. Yes, Mr. Chairman, we would to this extent. The word collateral needs to be further defined or to be defined.

For example, if the medical information that we receive reveals evidence of fraud in one of the programs and we made a case and turned that information over to the Department of Justice for prosecution and the Department of Justice declined to prosecute for whatever reason—either the value is not that great or the individual may have some mitigating circumstances—we, for example, would not consider it collateral to then refer that matter to, say, the Health Care Financing Administration for administrative recoveries even though that would be considered collateral in the sense that it is not a criminal prosecution and it is no longer going to be resolved in a criminal fashion.

However, we feel that if there are moneys which are due the United States due to the misdeeds of a particular provider and we were able to prove that, based upon the information from the

medical records, we would want HCFA to be able to recover those moneys for the Government.

So I think primarily I have trouble with the term collateral. And, also, I think in most of our experiences, whenever there is a blanket prohibition down the road, we find the need for exceptions.

Mr. PREYER. You want to be sure that collateral doesn't block any prosecutorial activity.

Are there any further questions of this witness?

Thank you, Mr. Lowe. We appreciate your being here.

Off the record.

[Discussion off the record.]

Mr. PREYER. Back on the record.

Mr. WEISS. I am sorry I missed Mr. Lowe's testimony because I was testifying at another subcommittee meeting, but I am delighted to have you here.

Mr. LOWE. Thank you.

Mr. PREYER. Thank you.

Our final witness today is Dr. Sidney Wolfe. He is to appear for the Health Research Group. Maybe he wanted to be sure Mr. Erlenborn heard his comments. We will make a quick check to see if he is here.

Without objection, we will be in touch with him at a later date in order to get the benefit of his testimony and questions concerning it.

Mr. PREYER. The subcommittee stands adjourned until Saturday at 1:30.

[Whereupon, at 11:44 a.m., the subcommittee adjourned, to reconvene at 1:30 p.m., Saturday, July 14, 1979.]

PRIVACY OF MEDICAL RECORDS

SATURDAY, JULY 14, 1979

HOUSE OF REPRESENTATIVES,
GOVERNMENT INFORMATION
AND INDIVIDUAL RIGHTS SUBCOMMITTEE
OF THE COMMITTEE ON GOVERNMENT OPERATIONS,
Indianapolis, Ind.

The subcommittee met, pursuant to notice, at 1:30 p.m., at Fesler Hall, Indiana University Medical Center, 1100 West Michigan St., Indianapolis, Ind., Hon. Richardson Preyer (chairman of the subcommittee) presiding.

Present: Representatives Richardson Preyer, David W. Evans, and Thomas N. Kindness.

Also present: Robert Gellman, associate counsel; and Thomas G. Morr, minority professional staff, Committee on Government Operations.

Mr. PREYER. The committee will come to order. It's a pleasure for the committee to be here in Indiana, at the Indiana University Medical Center today. My own home State of North Carolina I think helps share some of the same interests in your State. One of the things we are proud of is our medical facilities, and certainly here in Indiana you have some of the finest in the country. I think it's appropriate that the committee hold a hearing here, where the largest medical school in the country is located and where one of the great pharmaceutical houses, Eli Lilly, I suppose the largest in the country, is located and where you have a Congressman who reminded me of those two facts and suggested that this would be an appropriate place for us to continue with our hearings.

Dave has played an important role in our earlier hearings, and we are grateful for his active interest in the work of the subcommittee. I am from North Carolina, and so I am taking advantage of the gentlemen from Ohio and Indiana. It is somewhat similar to Indiana. We are the same size, about 5 million people. We have 11 Congressman just as you have, and we have the consuming interest in basketball that you have. The ACC is now one of our most popular industries.

But we are not interested in basketball today. I think fine medical facilities is something else that we share in common.

Today we are here to discuss legislation designed to protect the confidentiality of medical records. We have already held, as a subcommittee, 5 days of hearings. This is our first opportunity to take a look at this legislation from a non-Washington perspective. This is our first field hearing.

There are two different bills before the subcommittee that we are considering. One is a bill, with a number H.R. 2979, which is

the Federal Privacy of Medical Records Act, which I introduced last March. The other bill, H.R. 3444, is the Carter administration's version of a medical privacy bill. Both would give patients the right to inspect and correct their medical records, and both define the circumstances under which a hospital could make disclosures without the consent of the patient. So it's in the framework of those two bills that we will be hearing testimony today.

We are very honored on the subcommittee to have with us today, besides your host Congressman David Evans, the ranking Republican member of the subcommittee, Tom Kindness. Congressman Kindness was kind enough to drive 100 miles or so to be here today. He has a wonderful name for a Congressman. In debate on the floor not long ago, one of the Congressmen forgot his name and referred to him as Congressman Friendship. He has been a very active and interested member of the subcommittee, and I would like to call on Congressman Kindness for any opening statement that he might have.

Mr. KINDNESS. Thank you, Mr. Chairman.

I share the pleasure in being here this afternoon. I am like the Sunoco dealer. I can be very friendly. I guess you don't get that commercial around here.

I would like to point out that it's purely by chance that I am wearing a tie with the Indiana State seal on it today. This occurred as the result of a mistake I made in a men's clothing store in Cincinnati some few years ago. When I saw it, I liked the tie. I discovered later that it had the Indiana State seal on it. I think it's just great, though.

I love to have the opportunity to visit Indiana, the State of birth of my wife. So, I have got to like it. She was born in Bloomington. In case any of you are not familiar with it, that's where the rest of the university is.

I think we all share the concern about the use of medical records information in the light of the need for the preservation of the right to privacy of individuals about whom those records are collected and the uses to which those records are put. The hearing process, such as we are engaged in here today, of course, is aimed at seeking the facts relating to the field of legislative interest which is being pursued. The hearing process is not a matter of making news or seeking headlines or sensationalizing, in fact, to some it may be that some of the hearing process may seem a bit dull sometimes.

But we are very much concerned with the serious aspects of records and what they mean to people. This subject is not the least bit boring to those who are concerned about the disclosure of information they consider within the scope of their privacy.

It's my opinion that we should proceed with the proposed legislation that we have before us, deliberately and cautiously. Chairman Preyer should be commended for the careful and thoughtful tone of the hearings that have been conducted up to this time, in keeping with his very judicial manner.

There are a number of difficult questions embodied in the bills under consideration. For example, one of the questions that we have to explore fully is whether the States may be able to do a better job of protecting individual medical records privacy than the

Federal Government. Often when the Federal Government gets involved in an issue, it compounds the problem that it sets out originally to solve—much like the elephant which, having stepped on the partridge, then decides to care for the eggs of the partridge that were left without a parent by sitting on the eggs. We have seen that sort of thing happen with a heavyhanded Federal Government often enough.

So it's particularly appropriate that we cautiously approach the role of Government in this very important area. I look forward to our hearing here and subsequent ones, concerning the various important points that will be brought out by the witnesses. And we appreciate participation of the witnesses here today and Congressman Evans for arranging the hospitality of the University Medical Center today for us.

Thank you, Mr. Chairman.

Mr. PREYER. Thank you, very much.

We are now ready to begin with our witnesses. And since we are in Dave Evan's backyard and he is far more familiar with these witnesses than I am, I am going to turn the chair over to Dave and ask him to present our witnesses and conduct the hearing from this point on.

Mr. EVANS. Thank you, very much, Mr. Chairman.

I would like to also welcome my colleague Mr. Kindness here to Indianapolis. I am very appreciative of the fact that you are able to be with us at this field hearing today.

I would also like to express my thanks and I am sure both Congressman Preyer and Congressman Kindness' appreciation to the subcommittee staff and to my staff, and also to Suetta Kehrein from the university and the other people who helped provide the arrangements for our hearing this afternoon. We certainly have a number of very distinguished guests with us today in the audience.

I would especially like to take a moment and recognize Dean Beering of the Indiana University Medical School. Dean Beering, if you would, stand up and let everyone see where you are. We thank you for your hospitality here this afternoon.

Also, I recollect a number of times when Indiana and North Carolina were associated with one another, either on the basketball court or off the basketball court. In fact, I think one of the most exciting college basketball games I ever witnessed was down at Indiana University, the Bloomington campus as you mentioned, Tom, when, I believe it was, Billy Cunningham was playing for North Carolina at that time. So I am very appreciative of having a Congressman from North Carolina here and from our neighboring State of Ohio.

I would like to take a moment to share a little information which has already been brought out in hearings on this subject matter by the subcommittee in Washington, D.C., because as the chairman and Mr. Kindness have indicated, I think it will help to set a framework for our hearing here this afternoon. Americans average over five visits per year to physicians for medical advice and treatment. Each of these contacts typically generates either a new medical record or additional entries in existing records. The recommended minimum retention period for such information is between 10 and 25 years.

The tremendous growth in the amount of highly personal medical information in the hands of care providers, along with growing demands routinely satisfied for access to such information by third parties not involved in medical service delivery, has resulted in a serious erosion of the confidentiality of the medical care relationship. Today, the decision as to whether or not to disclose medical record information to a third party lies within the discretion of the medical care provider. This discretion has been left unfettered by the courts which have, for the most part, upheld the autonomy of the medical care facility to control the dissemination of medical record information.

The parameters of the problem and the pressing need to find a solution stem both from the nature of the information collected in the context of the doctor-patient relationship and the variety of nonmedical uses to which it is all too often perhaps applied. Medical records typically contain much more than a straightforward documentation of the medical illness of a patient and the treatments administered to him or her. Records often include information regarding the patient's personal habits, social relationships and attitudes and preferences as perceived by the physician.

As noted by the executive director of the American Medical Record Association, "A complete medical record may contain more intimate details about an individual than could be found in any other single document." A partial list of those who frequently seek access to this personal information would include insurance companies, government service payers, welfare agencies, researchers, employers, licensing agencies, public health and law enforcement agencies, and credit reporting agencies. While the need for information by such third parties may often be very legitimate, the tremendous potential for unnecessary and unfair intrusions on the privacy of a record subject is inherent in a system which places no set determined limits on the availability of a recordkeeper to disclose such highly personal information. The dangers of indiscriminate disclosure or irrelevant and at time perhaps inaccurate information is sometimes compounded by present practices which may deny an individual an opportunity to inspect his or her medical records and to correct mistakes contained therein.

I would like at this time then, Mr. Chairman, to proceed and introduce our first witness this afternoon, Dr. John Marsden of Eli Lilly. He has been the executive director of the Lilly Research Laboratory since June of this year. Dr. Marsden was engaged in the private practice of pediatrics for approximately 13 years before joining the Lilly Medical Communications Division in 1968. He became the manager of Medical Editorial Services in 1970 and was named director of medical research in 1972. In 1973, he became the director of clinical investigation. He is a fellow of the American Academy of Pediatrics and a diplomate of the American Board of Pediatrics.

Dr. Marsden, please proceed with your prepared statement.

**STATEMENT OF DR. JOHN MARSDEN, EXECUTIVE DIRECTOR,
LILLY RESEARCH LABORATORIES, ELI LILLY & CO., INDIAN-
APOLIS, IND.**

Dr. MARSDEN. Mr. Chairman, members of the committee, I thank you for this invitation to participate in these hearings on legislation concerning the confidentiality of medical records.

As I have been introduced, my name is John Marsden. I am a physician and now serve as the executive director of the Lilly Research Laboratories.

Eli Lilly & Co. is engaged in the research, development, production, and distribution of pharmaceutical products and therefore has a significant interest in legislation relating to these activities. We believe that patient privacy is a personal and fundamental right, as I will point out later in my statement.

Lilly supports the concept that, except in special circumstances, the patient has the right to decide if—and what—private information about his or her medical history is made available to others. It is imperative that the rights of the individual be weighed against the needs of society. You deserve commendation for providing the vehicle and the forum to encourage a thorough discussion of this important issue.

Historically, physicians and other health care professionals have observed patient confidentiality as part of the code of ethics underlying the practice of medicine. State laws preserving the physician-patient relationship have also formed part of this protection. In the past, these controls appear to have worked well.

However, today more health care is being provided by large institutions and less by individual doctors. The Federal Government is providing, paying for, and regulating more of these medical services. Third-party payments now finance a large part of the health care provided by hospitals.

Researchers, third-party payers, law enforcement officials, and others need medical information in connection with transactions involving the patient, and these people are not subject to the codes of confidentiality governing the conduct of physicians.

Such changes in the health care delivery system and in the technology of recordkeeping may result in medical records being beyond the direct stewardship of health care professionals. A growing amount of medical information is being stored in computers, which presents special problems of security and unauthorized disclosure. It is important to consider ways to preserve the privacy of medical records in spite of these changes.

Eli Lilly & Co. sponsors a large number of clinical trials each year, both on drugs not yet on the market and continuing studies of existing medications. Therefore, section 124 of H.R. 2979 dealing with health research is of particular interest to us. In these clinical trials, generally undertaken in major medical institutions throughout the country, but in some cases in private physicians' offices, confidentiality of the patient is observed. In the data that we request, the patient is not identified by name, but by number and initials. The only exception to this is the Lilly Clinic here in Indianapolis, where the Lilly physicians deal directly with patients or healthy volunteer subjects in the early clinical trials.

I should add that the clinical trial patients sign an informed consent agreement with the clinical investigator, in which they state they are willing to take part in the investigation and in which they agree to allow data pertinent to that clinical trial to be used for research purposes. At the same time, the patients are informed about the drug that is being tested on them.

The clinical trial data that we request, and that are compiled for submission to the FDA, do not include the names or addresses of the patients who have taken part in the investigations. We do not need this information; our interest lies in the overall results of the tests.

However, it is important that there is an established method of tracing specific case histories through the physician who has conducted the trial. For this reason, the removal of the identifier in the clinical trial records, that allows the patient to be traced, would not be a good idea in our opinion.

I would like to mention here that the Food and Drug Administration recently issued proposed regulations for sponsors and monitors of clinical trials that would require the sponsors, for example Eli Lilly & Co., to review primary source documents in order to verify the clinical investigators' case reports. We do not agree with this proposal because it is an unnecessary invasion of the patient's privacy. We have informed FDA of our position on this matter through the submission of comments on these proposed regulations. We also feel that Government inspectors should not identify case records with individual patient names without cause.

H.R. 2979 recognizes that there can be a conflict between the individual's right to medical confidentiality and the legitimate needs of public and private organizations, such as researchers and law enforcement officials, for identifiable medical information. A delicate balance needs to be maintained here. Any regulations allowing for disclosure of this private information, with or without the patient's consent, need to be sharply defined. In any event, we believe that such regulations will be difficult to administer. As a general rule, if a patient agrees to participate in medical research, the data should be available to the medical community without further approvals, as long as the individual patient is not identified.

The bill also proposes that procedures should be set up allowing individuals to inspect their own medical records in hospitals. We understand the need for some patients to have access to these records, but we have serious doubts about the unrestricted right for all patients to review all their records, at any time, especially just for the sake of curiosity. The burden on the staff of hospital record rooms would be enormous.

In other words, there should not be unlimited access to hospital records. If there is a valid reason presented, such as to satisfy legal or insurance needs, then the patient should not be denied. Such access is currently available. It is doubtful that the administrative burden and cost to medical institutions would be offset by demonstrable benefits if the provisions of H.R. 2979 on this particular issue were to become law.

In conclusion, we support the concept of the protection of privacy of medical information, which is embodied in H.R. 2979. Our per-

ception is that there may be a potential for erosion of confidentiality in today's medical care relationships, and that this possibility needs to be examined as this committee is doing. We support the view that individuals should be allowed more direct control over the disclosure of their personal medical information to outside parties.

Thank you again for this invitation to be here this afternoon. If there are any questions, I would be happy to try and answer them.

Mr. EVANS. Thank you very much, Dr. Marsden. I would like to ask one or two questions and then recognize my colleague Mr. Kindness and Chairman Preyer.

If each State passed its own laws regarding medical records privacy, undoubtedly I think the country would end up with a number of different rules and regulations and legislation within the various States governing the researcher's use of medical records. Do you foresee any difficulty, at least on the part of Eli Lilly, in complying with what might be a mosaic of varying laws across, over this country, as you conduct your research, or would it in your opinion be better to have one uniform Federal law in this area?

Dr. MARSDEN. Of course the problem that might arise in individual laws, naturally would depend on the laws as you indicated.

Our position would be that we really don't need patient identification. As I mentioned in my statement, I don't know of any instance, other than the exception I made of the Lilly Clinic, where we as a company have to know or want to know the individual patient. We have submitted to us a case report form, which contains the information on that patient that's pertinent to our clinical trial; and that's what we want. We need a way to relate that piece of paper back to the investigator who can then relate that identifier with the patient. But we, as a company, would never want to go back directly to the patient.

So if the law that was passed would provide in each State that medical information, with the appropriate kinds of controls could be made available for medical research, then I don't see that as a problem for Eli Lilly.

Mr. EVANS. Chairman Preyer.

Mr. PREYER. Thank you very much, Dr. Marsden, for I think a very balanced statement which explores the problems that have developed and I think implicitly expresses the hope that we don't do more damage than we do good by trying to correct some of the problems.

In the days when we could rely solely on the Hippocratic oath, to the effect that I, as a physician, wouldn't reveal anything which ought not to be revealed, things were simple. And I wish that would operate today, fully, in every area. But as you point out, many more institutions have become involved in medical care, institutions that don't operate under the Hippocratic oath; and that's generally where the problem is.

You are primarily concerned with Eli Lilly on the question of research and identifiable medical records. Both of the bills would permit disclosure of identifiable medical records to researchers, if it's determined that the project—I think the language of the bill is this—"is of sufficient importance so as to outweigh the intrusion into the privacy of the individual that would result from the disclo-

sure." Do you think that's a realistic standard? Is that a standard that can be meaningfully applied?

Dr. MARSDEN. I don't want to seem to evade the question, but I have a little problem here. I suspect there are instances where identifiable information, patient individual identifiable information, needs to be used in research. And I can't speak for all research; I can only speak for pharmaceutical research as conducted by Eli Lilly & Co. But I think that individual identification in medical research is usually not required. I think that, most times, the useful information in medical research can be perfectly useful if the patient is not identified as an individual in the publication and the general dissemination of information, because you are compiling large numbers of experiences or maybe small numbers of experiences. But the identification of the individual patient, as I think, is generally not needed.

Now I would think when that individual identification is a necessary part of that report, to disseminate and make that information useful, then I certainly feel that it should not be disseminated without the individual agreeing to it.

As I have also said in my statement, I think though if the individual is not identified, once they have agreed to the information being disseminated, there should not have to be further permissions and approvals, that that can be used by multiple researchers if necessary.

Mr. PREYER. Then from your experience, you don't feel that it's really necessary to even have an exception that the medical record be identified where practicable with the name of the person. It hardly ever comes up in your situation.

Dr. MARSDEN. In our situation, we really have no need to know the individual patient. We have a need to identify a case record with an individual whose chart is in the possession of the investigator; and we have to be able to go back to the investigator, identify that case report that he has given us; and then he can identify a patient. But we, of ourselves, never ask for that identification. Our case reports come in with an initial and a number to identify it, and a number for the investigator, so that we can correlate an investigator and a patient number.

Now I am sure there are research situations probably in some kinds of epidemiologic research, where you may have to identify the patient in order to make that research and tabulation useful. In that case, I think we need to provide in any bill that we develop a mechanism by which it can be made useful if the patient agrees.

Mr. PREYER. I suppose something like the swine flu epidemic, for example. I don't know how that was handled epidemiologically, but I can see how it may be where you need to know some answers fast; you might need to know the history and the background of the individuals and which hotel they stayed at and so forth, where you would about have to have names, I would think.

Dr. MARSDEN. Yes. If someone other than the physician is conducting that study, they would have to identify the patient.

Mr. PREYER. I am impressed with the way Eli Lilly conducts its research. I hope all the pharmaceutical companies are being as careful as you are about privacy matters. I don't think there would be any problems with the way you handle it.

Mr. EVANS. Congressman Kindness.

Mr. KINDNESS. Thank you.

Mr. Chairman, I hesitate to disagree with you, but I have identified one area of concern, if it isn't a problem.

In conducting research related to the development of pharmaceutical products, if you have had something that went on the market after being through all the clinical tests and so on and it later developed in widespread clinical use that there was a serious side effect. And you need to have a way, an effective way, to check back after some passage of time to the control group that was used in the study. How would you do it? The group might very well be dissipated by the system that you have described in use by your company, in that you are dependent upon the contact remaining between the physician, investigator, and the patient? If that is lost, then you don't have a way to get back to that group, do you?

Dr. MARSDEN. If the medical record of the individual were somehow or other no longer available, what you say is true.

Generally, however, as I understand it, most records would be, and certainly hospital records, would remain in the hospital. And the likelihood of those hospital records being forever lost is not very likely, although any record, individual record, could certainly be lost.

I think we made a statement here that we do feel that we need to have a mechanism by which we can get back to an individual patient, but we would do that through the investigator. Now the alternative to that would, of course, be for us to collect all these names and addresses of the individual patient and have that as part of the medical record, with the supposition that then we could go back. We would probably be in a far lesser, less satisfactory position to go back and trace that individual than would the private physician or the hospital in that location, since our clinical trials may be worldwide.

Mr. KINDNESS. Because of the indirectness of the relationship, I would think that to have an ideal set of circumstances, to protect your company's interest at a later date and so on, would be to have as much identification as possible, including, say, social security number, as well as name and address, and some way that you could actually use the information to trace that person over a period of years if necessary; and yet you must, for various considerations, not wish to proceed in that manner.

Is it a valid consideration that there may be the need for those doing research in not only epidemiological research but also in the development of drugs or pharmaceuticals to be able to tie back to the clinical test group patients directly, without going through the physician involved, the investigator?

Dr. MARSDEN. In several hundred clinical trials in which I have been involved, with the exclusion as I mention earlier of the Lilly Clinic in which we are the investigator, I have never had that occasion arise where we wanted to get back to an individual that we couldn't. So what you are saying theoretically is could it happen that the record would be dissolved and gone and no longer available, and the only way to get back would be through our knowledge. You are certainly correct, Congressman, and that could happen theoretically. I have never know of an occasion in my time at

Lilly's, in several hundred investigations, where we have had that happen.

Mr. KINDNESS. It's not a particularly practical problem then.

Dr. MARSDEN. It has never happened to my knowledge.

Mr. KINDNESS. The data that is collected in the course of your research work might in some cases, it seems, become subject to subpoena in a lawsuit for some reason or conceivably in a criminal action. Do you think there are protections that ought to be built into the process by which those records might become subject to subpoena, so as to protect further the identity of the individual? In your case, in your company's case, you don't have the identifier. But would those who might not be operating in the same way, where the identification of the individual is there?

Do you have any thoughts to offer on whether there ought to be some limitation on what the courts would require by way of disclosure, how to protect the identified individual patient in those cases? I am speaking of research type data now.

Dr. MARSDEN. My feeling would be that that individual who participated in research has the right to privacy, as any other individual; and we should make every effort to keep that private to the degree that we can.

Now there may be occasions of epidemiologic studies and there may be occasions in criminal proceedings where that information has to be made available despite the patient's willingness and desire to have that done. And I think that's included in the bill, as I recall it. I am sure that there are situations where you may have to have access to medical information for good and justifiable purposes without the patient's permission.

As far as we're concerned, as a company, again I will be repeating myself. We don't have that—haven't had that—as a problem.

Mr. KINDNESS. Is there much shifting of information among different researchers? I suspect there would not be, of course, as between one pharmaceutical company and another, competitors. But in general within the health care field, are you aware of there being any swapping of information or helping one another with research data that you might develop or your company might develop; for example, someone else conducting research toward the treatment or cure of a particular disease may have been following some parallel course of study? Would you care to comment about anything that you have encountered in that area that might, in some cases at least, have resulted in the disclosure of identifiable information?

Dr. MARSDEN. I can't think of a situation where identifiable information would be disclosed. I can think of situations where we have cooperated with other people in studies. For instance, we may be studying a drug and looking at a certain number of cases with a certain disease and the effect of the particular drug that we are studying on that disease, and we may have compiled a significant amount of data. There may be another researcher somewhere in the country completely independent of us that is studying that particular disease and alternate forms of therapy, and he may want to—He may come back to us and ask us what our experience has been with this disease and this drug, and we would probably disclose to him, in summary information, but there would be noth-

ing we would give him that would identify an individual patient, if for no other reason that we don't have the identifier anyway. But we wouldn't even send to him—In general, we wouldn't give him the patient number or even initials, necessarily. So we wouldn't identify an individual patient in that situation, just give him a summary of our data. And we have done that from time to time.

Mr. KINDNESS. What about the other way around, information coming to you, Eli Lilly?

Dr. MARSDEN. Well, of course that's what we do. That is what we pay for, and that's our role in dealing with investigators, is to set up studies to look at a particular drug and a particular disease. Then they provide us with information.

But as I said earlier, what they provide us with is that segment of the patient's medical history that pertains to that particular study. But we don't get that patient's complete medical history. We don't know everything that happened to them in their entire life. They have provided us the information that we have asked for, in the case report form that we have developed, to get the data that we need to support the new drug application.

Mr. KINDNESS. I believe, Mr. Chairman, I have exceeded my time already. I will yield back.

Mr. EVANS. OK.

Thank you, Dr. Marsden, for your testimony. We appreciate the opportunity to talk with you this afternoon.

Our next witness will be Mr. Michael Reindl, who is the assistant executive director of the Indiana Pharmaceutical Association, and has been with that organization since 1977, a graduate of Rutgers University, and has earned his Ph. D. at Ohio State University.

Mr. Reindl, please proceed with your statement.

STATEMENT OF J. MICHAEL REINDL, ASSISTANT EXECUTIVE DIRECTOR, INDIANA PHARMACEUTICAL ASSOCIATION, INDIANAPOLIS, IND.

Mr. REINDL. Mr. Chairman, members of the committee, I think you for the opportunity to respond to the proposed House bills 2979 and 3444, dealing with the privacy of medical records.

We are in agreement with the viewpoint embodied in this bill that the right to privacy is a personal and basic right protected by the Constitution of the United States and that the right to privacy could be increasingly threatened by the collection, maintenance, use and dissemination of medical information.

To a large degree, the application of this proposed legislation to the practice of pharmacy hinges upon the definition of the term "medical care facility" as spelled out in part A, section 101(9)(A), which is page 6 of House bill 2979.

The question which arises is the definition of the word "entity" on line 9 on page 6, and whether such definition would include pharmacies. Should pharmacies be included under this definition, then we have a problem with the section of the bill entitled "Notice of Record Keeping Practices," page 11. We feel that giving printed notices to all patients would impose a tremendous paper-work burden upon the pharmacist, pharmacists whose time for patient care is already reduced to a minimum by existing and often

burdensome paperwork requirements of private insurance as well as Government and State programs.

Our main interest with regard to the bill centers on the section entitled "Authorization for the Disclosure of Medical Records," beginning on page 12. As you know, pharmacists are required by private health insurance companies, as well as Government and State agencies, to complete rather lengthy and detailed forms when dispensing medication to patients. Thus, pharmacists collect a tremendous amount of data which, in turn, is forwarded to these companies and agencies.

We are, as we have stated, in agreement with the philosophical principle that the right of the individual patient to the privacy of his medical records is very important; and we, therefore, worry about the flow of the medical information the pharmacist gathers and transmits, once this information has left the pharmacist's hands.

Possibly this bill ought to focus more on the dissemination and ultimate utilization of this great amount of data. It is conceivable that this data might be of great interest to parties other than the immediate recipient of these medical records and might be used for purposes other than those strictly necessary to maintain the health of the patient. We know that many of our member pharmacists ask themselves whether the collection of all of this data is necessary for the immediate transaction at hand, which is the dispensing of medication and reimbursement for the services rendered.

We would hope that achieving the goal of greater protection of the individual's right to privacy of his medical records would have, as a beneficial side effect, a reduction of the tremendous amount of paperwork which places such a burden on the pharmacist.

Thank you, Mr. Chairman, Congressman Evans, and Congressman Kindness for affording us the opportunity to present our viewpoint.

Mr. EVANS. Thank you, Mr. Reindl.

I don't intend to speak for the author of the bill, but I think that it is not the intent of H.R. 2979 to cover pharmacies except if the pharmacy is run by a hospital or a medical care facility. I think, in fact, the language is drawn so that it does not cover the corner drugstore, for example. I just want to make that statement, and perhaps Chairman Preyer will comment further.

I did have one or two questions. There are several bills currently before Congress—Senate side Senate bill 1075 and, on the House side, H.R. 4258—that would place limitations on the disclosure of prescription records. I just wonder, first of all, has the Indiana Pharmaceutical Association taken a position on either of those two bills currently before Congress?

Mr. REINDL. No, sir, we have not. That would be more properly the role of the APA, the American Pharmaceutical Association; and I am sure that they have.

As far as the disclosure of these records within our State, of course we are covered by our State pharmacy laws.

Mr. EVANS. Is cooperation with researchers encouraged by your association here in the State?

Mr. REINDL. I would say, in general, we have a cooperative attitude. I qualified that, because it depends on what the research is.

Mr. EVANS. Do you recommend that only nonidentifiable information be shared with researchers?

Mr. REINDL. I would again, qualifying, depending on the type of research, say yes.

Mr. EVANS. Chairman Preyer.

Mr. PREYER. Thank you.

Congressman Evans has explained the limited reach of our bills over pharmacies, and I think it's limited on the basis that pharmaceutical records, prescription records to be more accurate, are not as sensitive or as personal information as a person's medical record would be. Therefore, we don't have to be quite as concerned about it. I am wondering if we are right about that.

There have been stories in the newspapers, which I am sure you have seen, and there has been testimony before congressional committees recently about private detective agencies who have been trafficking in, who have been stealing and selling medical information, medical records. Do you know whether there has been any such abuse with prescription records? Have you ever heard of a private detective agency, for example, attempting to steal or get access to prescription records for some nefarious purpose?

Mr. REINDL. No, sir. To my knowledge, I do not know that.

I would agree with your statement that, in some cases, a pharmacist's records can be quite sensitive, especially in those cases where you can infer from the type of medication the patient receives what the illness might be, and so forth. But I would imagine since, in most instances, the types of records pharmacists keep are part of a larger medical record, that that problem does not exist in the fashion that you are talking about.

Mr. PREYER. There are some bills proposed in the Senate, in particular, that would permit disclosure of prescription records to Federal or State officials, law enforcement officials, for example, in the course of their official business. I wondered if those are pretty broad categories of disclosure. I wondered if your association has had any opportunity to look at those bills and whether you are concerned that any proposed legislation may be allowing too broad access to prescription records by, say, law enforcement officers.

Mr. REINDL. Well, sir, again that's not entirely within our province, because we are more concerned with the regional aspects of it.

The conduct of a pharmacist with respect to the confidentiality of the medical records he maintains of his patients, within our State, is primarily covered by the Indiana State laws governing pharmacies. Those State laws State—I won't quote the whole thing, just a few sentences, if I may.

"A pharmacist shall hold in strictest confidence all drug orders, records, patient information" and so on. The law which is section 15 of the Pharmacy Practices Act goes on to say that the pharmacist may divulge such information only when it is in the best interest of the patient or when requested by the board—and the board, in this context, means the Indiana State Board of Pharmacy—or its representatives or by a law enforcement officer charged

with the enforcement of laws pertaining to drugs or devices for the practice of pharmacy.

So I would maintain that presently our state law, I believe, in a less complex of a fashion than this bill would do, but it does maintain a rather strict confidentiality quality to the maintenance of medical records by a pharmacist.

Mr. PREYER. It sounds from that law as if a private investigator would not be free to come in and have access to prescription records.

Mr. REINDL. Yes, sir. He would not.

Mr. PREYER. But law enforcement officers, which have a valid need for records, would have the opportunity.

Mr. REINDL. Yes, sir.

Mr. PREYER. Thank you, Mr. Reindl. We appreciate your testimony very much.

Mr. EVANS. Congressman Kindness.

Mr. KINDNESS. Mr. Reindl, your statement on page 2 points out that pharmacists are required by private health insurance companies as well as Government and State programs to complete rather lengthy, detailed forms when dispensing medication to patients; thus, pharmacists collect a tremendous amount of data which in turn is forwarded to these companies and agencies. The members of your association are subject to a situation there about which I am wondering a bit.

You are required to provide that information to the insurance companies and third-party payers, but you certainly ought to be protected in making that disclosure if there is some broad provision made a part of the law which says nobody shall disclose anything. I am glad you brought up this point, because it hadn't occurred to me before. There are some providers of parts of health care service who routinely need to disclose that information to the principal provider or the insurance company or third-party payer. You have raised a good point which we don't want to accidentally create difficulty within the legislation.

Similarly, hospitals and other patient care facilities do maintain a good many prescription records or records of prescription transactions that would be supplied by the members of your association. Are any particular steps taken that you know of to protect the confidentiality of those records in transit or in the process of getting back to the institution that initiated the treatment?

Mr. REINDL. I am not entirely sure, sir, what you mean by "particular measures" taken. We tend to entrust those matters to our fine postal folks and hope and pray that, in the first-class mail, they will reach the point that they should reach. There hasn't been, as far as I know, any particular problem with that part of it.

Mr. KINDNESS. It would be very typical that it just goes in the mail, rather than any other means of transmission of that data.

Mr. REINDL. Yes, sir. That's right.

Mr. KINDNESS. Thank you. I don't have any further questions, but I think your testimony here today is a bit thought provoking and has caused me to look a little bit more carefully at part of this as it relates to the pharmaceutical business, profession. I thank you, very kindly.

Mr. EVANS. Thank you.

Mr. REINDL. Thank you, gentlemen.

Mr. EVANS. Our third witness this afternoon is Stan Huseland, who is the director of government affairs at Blue Cross and Blue Shield of Indiana. Stan is a native of Washington State, a graduate of the University of Washington, and has been associated with Blue Cross and Blue Shield of Indiana since 1969 in a variety of management positions. As I said, he is currently director of government affairs.

Stan, if you would also like to identify your associate for the record here, why, then please feel to proceed with your statement.

STATEMENT OF STANLEY A. HUSELAND, DIRECTOR, GOVERNMENTAL AFFAIRS, BLUE CROSS AND BLUE SHIELD OF INDIANA, INDIANAPOLIS, IND.; ACCOMPANIED BY DONALD J. VAN DYKE, VICE PRESIDENT, MARKETING ADMINISTRATION DIVISION

Mr. HUSELAND. Certainly, Mr. Chairman.

I have with me Mr. Donald J. Van Dyke, the vice president of the marketing administration division. He has a great deal of depth and experience in a number of functions of our company that are important to these hearings.

Mr. EVANS. Thank you.

Mr. HUSELAND. Mr. Chairman and members of the committee, we are pleased to be here to comment on the Federal Privacy of Medical Records Act and specifically our experience in Indiana on the general subject of preserving the confidentiality of personal information.

I would first like to describe Blue Cross and Blue Shield of Indiana. These are two mutual insurance companies formed in 1944 and 1946, respectively, under Indiana insurance laws, and regulated by the Indiana Department of Insurance. The companies through a joint operating agreement employ a common staff and market joint benefits. At the present time, Blue Cross and Blue Shield of Indiana insure about 2.1 million Indiana residents in the private competitive market, or about 40 percent of the population. In addition, we are the fiscal intermediary for the Federal Government, administering parts A and B of medicare in Indiana, and are fiscal agents for the State of Indiana in the medicaid program.

In common with other Blue Cross and Blue Shield plans, we differ in some respects from other health insurers. We have contracts with institutional providers to assure that providers initiate claims rather than our members, when possible. Our predominant coverage is a service benefit as opposed to indemnity. Our involvement with health care providers in cost containment programs and experiments far exceeds that of others who perform a more limited health insurance function. We mention these distinctions not only because they demonstrate we are different in beneficial ways, but also because the differences affect the amount of medical information we require to do our job properly.

In addressing the subject of the legislation, we share the subcommittee's concern for the protection of the public's right of confidentiality and privacy. We are proud that we have a long record of commitment to protecting these rights sensitively and thoroughly, while serving the financing needs of our members.

It is necessary, of course, to the business of health insurance to use medical information. This necessity has a corresponding responsibility to protect it from improper disclosure.

Previously, Mr. Marshall Crawford presented testimony on behalf of the Blue Cross and Blue Shield Associations to the subcommittee. His description of the data required generally applies to the way we conduct our business.

We require certain minimal information at the point of the member's enrollment. This normally includes name, address, social security number, and age of the applicant and dependents. At this point, we also ask for authorization for access to such medical records as may be necessary to pay claims according to contract.

Once the membership is established, we will need medical information only when a claim is made. The normal claim will require the identity of the patient, the physician, the facility, diagnosis, a description of services rendered, length of stay, and charges.

Of all the institutional claims received—and they totaled more than 1 million in 1978—about 98 percent are payable based on the minimal data on the claim form. However, there are claims which require further medical information in order to apply benefits accurately. These typically require a medical question to be answered, such as:

Is this cosmetic surgery? Is this procedure medically necessary? Were there complications or extraordinary circumstances which would justify reimbursement at a higher level than normal? Could the service have been provided in a less expensive setting? Could there be liability by workmen's compensation or medicare which should take precedence? Are there unusual patterns of practice which our utilization review people should check for possible abuse?

These questions are necessary parts of adjudicating claims accurately, while achieving the cost containment goals which Blue Cross and Blue Shield continue to pursue for our members.

The keystone of our commitment to confidentiality is the care with which this needed information is protected from improper disclosure. We recognize that the bill does not deal specifically with these protections, but we mention them because it's important for you to realize our attitude toward the subject.

First of all, all employees who use confidential information—our customer services representatives, claim processors, utilization review specialists—are provided training in the handling of confidential data and specific procedural guidance to assure adequate safeguards.

Two, access of employees to confidential data is restricted on a need-to-know basis.

Three, increasingly, we are developing our computer systems so that computer access can be restricted to employees assigned to that system. Computer terminals can only be activated by code, including a confidential password code known only to the specific terminal operator assigned to the specific station.

Four, our facility itself has a limited access program designed to assure only authorized persons have access to work areas.

Five, special precautions are taken with such sensitive records as psychiatric or substance abuse services. Processing of these claims

is assigned to specific persons using segregated files which are made secure from access by nonauthorized employees.

Six, requests to health care providers for more detailed information are made by registered nurses and the records are reviewed by health care professionals employed for that purpose. To assure that medical questions and medical records are handled appropriately, we employ 2 physicians, 43 registered nurses and one registered records administrator.

Seven, claims and other utilization reports to employers disclose only statistical or fiscal information.

Eight, medical information is not disclosed in customer service contracts.

These safeguards are samples of a long-standing commitment to protecting the interests of the members we serve. We understand the responsibility that accompanies this trust.

At the same time, we know from daily contact with these members that they want their health insurance service to be prompt, no more complex than necessary, and to be sensitive to all their needs: Privacy, convenience, cost, and personalized service, to name a few.

We take these commitments seriously. We strive for a level of excellence that will continue our leadership in a competitive marketplace. Customer satisfaction, in all its practical aspects, is the test for any organization which serves the public.

As to the bills before the subcommittee, we would offer the following comments, which are generally consistent with the testimony of the Blue Cross and Blue Shield Associations.

We do not believe that the best solution is to enlarge the Federal jurisdiction, to preempt the States, and to create a regulatory body of law attempting to govern all situations in all States with respect to medical records.

First, there is a high level of ethical commitment on the part of both health care providers and health care insurers to the protection of confidential medical information. I have described our own.

Second, in Indiana and in many other States the legislative and executive branches have shown a sensitivity to this matter. The Indiana General Assembly passed a law regarding computerized medical records in 1975. That same year, Governor Bowen created a Governor's commission on individual privacy, by Executive Order No. 7-75, to evaluate both governmental and nongovernmental sectors. That commission concluded, among its recommendations:

Private sector organizations should be encouraged to review their information practices and to develop voluntary codes of fair information practices. If voluntary efforts fail to achieve meaningful results and legislation regulating private sector information systems is determined to be needed, such legislation should be categorical rather than omnibus.

We submit this as evidence that there is active State vigilance on this subject.

Third, we believe that voluntary ethical effort is achieving essentially the same goals of the Federal bills, without the attendant disadvantages. H.R. 2979 is a reasonable legislative proposal; but as it is amplified, clarified and specified by regulations, we are concerned it will become predictably rigid, burdensome, and a source of considerable cost and inconvenience to the public we serve.

We see the contrast between regulatory and voluntary control in our dual roles as a private insurer and as a fiscal intermediary for the Federal Government's medicare program. We are absolutely committed to the same level of service and protection of privacy in both programs.

However, under the Federal programs, we see the accumulation of file drawers of procedural records under the Federal Privacy Act and the Freedom of Information Act, compiled at significant cost, which in 3 years have never been accessed by a beneficiary or by a Government agency.

We see inconveniences caused the public by stringent requirements that prevent an elderly man from looking after the affairs of his bedridden wife without legal permission and documentation. We are persuaded that the public objects to caution carried to this extreme.

Our position is both proprivacy and antiredtape. We would like to continue to have the commonsense discretion to serve our members in ways which do not compromise their rights to privacy.

To the extent that we and others in the private sector fail, then we have no doubt the State legislature and regulatory agencies will call us to account. And so will our members on whom our existence depends.

As to the specific provisions of H.R. 2979, Mr. Chairman, we support the comments and testimony of the Blue Cross and Blue Shield Association in its specific observations. We believe the bill should specifically acknowledge the flexibility necessary to patient authorizations obtained by health insurers.

We obtain an authorization from our members at time of application, which provides us with the authority to obtain the medical information to pay claims. Because claims under our system are most frequently generated by the provider rather than the member, we depend on this authorization to enable claims and claim information to flow to us as and when necessary to serve our members.

We would support requiring authorizations to specify generically the facility authorized to make disclosure, such as a hospital, and specify generically the party to whom disclosure is to be made, such as the insurance company. The authorization should specify the general purpose for disclosure. We believe that the time period for a health insurer authorization should be during the contractual period and that the authorization should terminate with the end of the insurance coverage. Any less flexible requirement would cause us to obtain authorizations with each claim, which would tend to defeat the customer advantages of having claims come straight from the provider to the Blue Cross and Blue Shield plan. It could add unnecessary and nonproductive costs.

We suggest the following specific comments with respect to H.R. 2979:

Part B, section 115(a)(4): For the reasons discussed above, we suggest clarification indicating that an event specified could include the termination of insurance coverage.

Part B section 115(c)—We believe a more flexible provision could achieve the intent here without encumbering hospitals which re-

spond to our members, to obtain a copy of our authorization for their records.

When a hospital which has contracted with Blue Cross of Indiana encounters a patient with a Blue Cross and Blue Shield of Indiana identification card, the hospital knows that we have the patient's authorization and knows the specific wording of it. Although the hospital may choose to obtain its own patient consent at this point, it would seem unnecessarily cumbersome to request us to produce our authorization before a claim can be submitted. The resulting delay would be in the interest of neither the facility nor the member, and no practical purpose is achieved by obtaining a standard document when proof of the document's existence has been demonstrated.

What we are saying there, Mr. Chairman, is that for our authorization to have validity, under the bill, it would have to be at the hospital. And in lieu of that, the hospital has evidence, proof by virtue of our identification card, that proper consent has been given; and the hospitals are aware of the form of that consent. To enable the viability of that authorization—our authorization—to continue to exist, we would like proof of the authorization to be sufficient, so there is not the transfer of copies of our authorization back and forth. It is quite important to our system of provider to initiate claim forms.

That concludes our specific comments on H.R. 2979.

We believe that should any Federal legislation be deemed appropriate to govern the flow of information in the private sector that it deal with principles and standards, that it encourage voluntary efforts, and that it allow States to carry out any administrative activity.

Mr. Chairman, we thank you, as well as our Congressman, Mr. Evans, for the opportunity to comment on the bill and to offer our suggestions and recommendations on the confidentiality of medical records.

Mr. EVANS. Thank you, Mr. Huseland.

Before this subcommittee in Washington, the American Medical Records Association testified that insurance companies frequently seek more information than is necessary for paying claims and that it is not unusual for a copy of an entire medical record to be requested. What is the practice of Blue Cross and Blue Shield of Indiana?

Mr. HUSELAND. Well, as I indicated in the statement, Congressman Evans, in 98 percent of the cases no information is necessary and required beyond the claim form.

I indicated some instances when additional information is necessary, either to adjudicate accurately or for a cost containment purpose and so forth.

We attempt to be as selective as we can. I appreciate and am familiar with the position of the American Medical Records Association and can envision their view of the process from where they are at. I doubt that they are familiar, in detail, with the requirements that apply in those 2 percent of the cases. There are occasions when the entire medical record is requested.

Mr. EVANS. How specific are the requests in those situations? Are there guidelines set up governing it?

Mr. HUSELAND. We have a request form that has perhaps a couple of dozen specific categories of requests, and those specific categories or some more specific one that might be specified are used whenever possible. However, there are times when the entire medical record is requested, most commonly, when it is necessary for a medical determination to be made by a board of consultants, other physicians; and perhaps it is in the nature of the profession that the resulting physician wants to make his determination with the same information before him as the attending physician.

Mr. EVANS. Could we please obtain a copy of that request form that you have mentioned, for the committee's records?

Mr. HUSELAND. Yes, sir. Certainly.

[Material follows:]



Blue Cross
Blue Shield
of Indiana

CLAIM

☐ INQUIRY

☐ NOTIFICATION

HOSP. NO.
PAT. NO.
CLAIM NO.

RETURN TO: AREA _____ FLOOR _____

PATIENT	ADM/SERV DATE	ID NO	TYPE <input type="checkbox"/> INPAT. <input type="checkbox"/> BANK-HOST <input type="checkbox"/> PAID NO _____ CLAIM <input type="checkbox"/> OUT-PAT <input type="checkbox"/> FEDERAL <input type="checkbox"/>
---------	---------------	-------	--

We need the following information to continue processing. Please reply on this form, complete attachments, or provide copies of documents requested, attach and return.

- | | |
|---|--|
| <input type="checkbox"/> ADMITTING DIAGNOSIS
<input type="checkbox"/> COMPLETE FINAL DIAGNOSIS
<input type="checkbox"/> SURGICAL PROCEDURES PERFORMED AND DATE OF EACH
<input type="checkbox"/> CHART HISTORY
<input type="checkbox"/> DOCTOR'S ORDERS
<input type="checkbox"/> OPERATIVE REPORTS
<input type="checkbox"/> PROGRESS NOTES
<input type="checkbox"/> X-RAY REPORT(S)
<input type="checkbox"/> NURSES NOTES
<input type="checkbox"/> PHYSICAL THERAPY PROGRESS NOTES
<input type="checkbox"/> SPEECH THERAPY
<input type="checkbox"/> OCCUPATIONAL THERAPY
<input type="checkbox"/> DISCHARGE SUMMARY
<input type="checkbox"/> EMERGENCY ROOM REPORTS
<input type="checkbox"/> NURSERY RECORDS | <input type="checkbox"/> PATHOLOGY REPORT
<input type="checkbox"/> ORIGINAL BILL ATTACHED
<input type="checkbox"/> MENTAL STATUS EXAMINATION
<input type="checkbox"/> TREATMENT PLAN
<input type="checkbox"/> URC REPORTS
<input type="checkbox"/> COMPLETE ITEMIZED BILLING
<input type="checkbox"/> CORRECT NINE DIGIT BLUE CROSS IDENTIFICATION NO.
<input type="checkbox"/> EXACT NAME OF THE BLUE CROSS MEMBER
<input type="checkbox"/> INPATIENT ADMISSION DATE
<input type="checkbox"/> OUTPATIENT SERVICE DATE AND TIME
<input type="checkbox"/> OUTPATIENT DATE OF ACCIDENT AND TIME
<input type="checkbox"/> NATURE AND PLACE OF ACCIDENT
<input type="checkbox"/> CITY IF OTHER PLAN MEMBER
<input type="checkbox"/> OTHER INSURANCE INFORMATION
<input type="checkbox"/> ACCOUNT NUMBER AND BENEFIT CODE |
|---|--|

DATE

SUPERVISOR/MEDICAL ASSISTANT

REPLY

DATE

SIGNATURE

☐ OUTPATIENT BANK HOST CLAIM

NAME AND LOCATION OF BLUE CROSS PLAN

(NOTE: IF THE PLAN IS NOT INCLUDED ON THE LIST OF PARTICIPATING PLANS AS INDICATED IN THE BANK HOST OUTPATIENT MANUAL, THE CLAIM MUST BE SUBMITTED TO THE HOME PLAN FOR CONSIDERATION.)

☐ APPARENT DUPLICATE ADMISSION/CLAIM

RECORDS INDICATE THAT THE ATTACHED INPATIENT ADMISSION NOTICE/CLAIM IS AN EXACT DUPLICATE OF A PREVIOUSLY REPORTED ADMISSION/CLAIM. IF A CORRECTION IS REQUIRED, PLEASE COMPLETE THE PINK CASE CORRECTIONS, FORM 41C-105 (C - 111). IF THERE ARE ADDITIONAL QUESTIONS, PLEASE ATTACH THIS CLAIM TO A CLAIM INQUIRY, FORM 35C-105 (C - 121) AND RETURN.

DISTRIBUTION

WHITE - FOR REPLY TO BLUE CROSS
YELLOW - FOR YOUR RECORDS

PINK - CLAIM PEND COPY

Mr. EVANS. Let me just clarify it then in my own mind. Do I understand, you are saying there are no written guidelines that would attempt to keep to a minimum the information requested in these cases, 2 percent I believe was the figure you mentioned, where more detailed information from that medical record is requested. Is that correct?

Mr. HUSELAND. I am not certain whether it's correct or not.

I am certain, by virtue of my conversations with the people who work in this area, that they are indoctrinated in their training and that the policy of giving them very specific choices, and for those choices to be made by professional medical personnel, is in pursuit of the company policy to not make massive requests except as necessary.

Mr. EVANS. Congressman Preyer.

Mr. PREYER. Thank you, Dave.

And thank you, Mr. Huseland, for your testimony. You have given us some good practical suggestions.

I would think the major effect of a medical records privacy bill, such as these that have been proposed, as far as insurance companies go, would be in the area of access by the insurance companies to records of patients. And to the extent that the authorizations for the disclosures of these records have become pretty much a standard procedure, it would seem to me that the impact of any medical records privacy bill on insurance companies would be quite limited. Isn't that the case? Do you foresee any big problems with the bill?

Mr. HUSELAND. Well, Mr. Chairman, having read the bill and having stated the two areas of concern, it would seem to impact adversely the way we function. I just wish to make that known to you, in that it wasn't clear that an authorization—I am speaking of our authorization, which we obtain from the member-patient—could be valid during the life of the insurance coverage. Although I have observed the testimony of Mr. Crawford, in which he also indicated that that provision might be helpful, the bill leaves us at least in doubt that it would be so interpreted.

And the other one is that our authorization facilitates a process, a process that is somewhat unique in the way we function, although it's quite parallel to the way medicare also functions, which allows this service to be provided without causing an active intervention on the part of the patient, so long as there is evidence provided.

The hospital does not have our authorization. They know it exists; they know the wording exists. And when they see our identification card presented, they know we have a valid authorization under existing laws.

Mr. PREYER. I don't think it is the intention of any of the bills to make any sweeping changes dealing with authorizations or the way in which you operate. We do want to make clear that what we think is the fact that its influence would be rather minimal on your operation.

You make some good points and raise some good questions on the preempting of the State's point, and that is something that is of concern to me. Dave Evans raised one reason why it might be thought wise to preempt the States when he asked of Eli Lilly, Dr. Marsden, whether when you are conducting research, if you have

different standards in a lot of different States, does that mosaic pattern cause complication? Would it be easier for Eli Lilly or any other researchers if there were a standard law applying, dealing with it? I gather from Dr. Marsden's answer that it hasn't been a particular problem, that the State law seems to be working all right in that area.

One other area that deals with the question—should the Federal Government do it or should the State government do it—has to do with the use of medical records in audit and law enforcement purposes. One of the major users of records for these purposes is the Federal Government. And one of the problems is, can a State properly regulate Federal access to their records with a State law saying the Federal Government must do this, that or the other to have access for auditing purposes or law enforcement purposes?

I don't know whether you are a constitutional lawyer, and I guess that's not a fair question to ask you. But that is more of a comment, that that's one problem that you might have in an area of leaving the matter solely to the States. The Federal Government might have to at least legislate in that limited area.

Mr. HUSELAND. I would certainly bow to the Chairman's constitutional knowledge.

Mr. PREYER. Don't give in too easily.

I think you have made some good points, and your testimony is very helpful to us. I appreciate it.

Mr. EVANS. Congressman Kindness.

Mr. KINDNESS. Thank you.

One of the statements on page 2 of your testimony was that at the time of enrollment certain basic information is obtained from the enrollee or member. "At this point, we also ask for authorization for access to such medical records as may be necessary to pay claims according to contract." At the time of enrollment and obtaining that authorization, is there anything else by way of checking on medical background or history or what have you, if for example there is some reason to look into a pre-existing condition situation; or is anything normally done to check immediately into the past medical record?

Mr. HUSELAND. To deal, sir, with the pre-existing condition, the contracts do in some instances have pre-existing clauses, but those determinations are made if and when a claim is submitted that would raise the question of a pre-existing condition. Nothing is done to make those determinations at the time of enrollment. With one exception, we ask for no medical information to determine the previous medical history of patients.

We have a policy of insuring anyone who asks us for insurance. There are no uninsurables.

We do have a fairly recent coverage for which we do ask for some medical information for the purposes of determining whether they would be eligible for higher or lower options. With that one exception, we obtain no information for the purpose—at the point of enrollment—for the purpose of deciding eligibility or pre-existing conditions and that sort of thing.

Mr. KINDNESS. But the higher option coverage, there might be.

Mr. HUSELAND. In this one newly introduced coverage which has yet to apply to 1 percent of our membership. It is that new.

Mr. KINDNESS. But it would be routine there.

Mr. HUSELAND. Yes, sir. Not anything beyond that filling out of a questionnaire, but it does involve that, yes, sir.

Mr. KINDNESS. But there would be no checking back to previous medical records.

Mr. HUSELAND. No, sir. No, sir.

Mr. KINDNESS. As fiscal agent, third-party payer for medicare, is your organization considered an agent under the Privacy Act?

Mr. HUSELAND. Yes, sir.

Mr. KINDNESS. Do you have any information at all that is available that would give an indication of what it has cost your organization to comply with the Privacy Act?

Mr. HUSELAND. Well, I think the accurate answer would be that it doesn't cost us. It costs the Federal Government, because we are reimbursed at the level of our costs.

But I did ask some of the people who know more closely than do I, if there was a way to quantify it. And I suppose I have gotten more of a feel for the problems it causes the beneficiaries than I did a way to total the dollar costs, in other words inconvenience costs. But, I couldn't answer with a factual dollar answer, sir. No.

Mr. KINDNESS. You wouldn't be able to indicate that it has had the effect of requiring employment of a particular number of people or anything of that nature?

Mr. HUSELAND. No, we couldn't make that assertion.

Mr. KINDNESS. Thank you.

Mr. EVANS. Thank you, Congressman Kindness.

I would like to recognize Bob Gellman of the subcommittee staff for a couple of questions now.

Mr. GELLMAN. In your statement, you raised a question about releasing the medical records. Hospitals have generally told us that they will not release medical information without having a signed authorization in their possession and that they usually get one when somebody asks them to submit a claim form on their behalf. That form is an authorization. And Marshall Crawford of the Blue Cross Association, who testified in Washington, also said that this was a standing practice.

I am wondering if things are a little different in Indiana.

Mr. HUSELAND. Well, I don't think so.

I have talked to Marshall Crawford, and I have talked to him about our concerns. I don't think we have any differences. I don't think there was a great deal of focus on the question of the insurer's authorization being valid at the point of the provider.

The hospitals have come commonly to get their own consent forms, but we feel it's important as an insurer to have the permission of our insureds for whatever we do on their behalf. And so, we are looking for validity of our authorization. There are times that arise when the hospital cannot practically get the consent.

I don't know what they do in the case of other insurers, but they are well aware that we have a valid consent form under existing law and so that there is no interruption to the claims processing. This could occur in emergency room situations and many others, that under our authorization those claims flow without the intervention of the patient and on the basis of the consent that they granted to us.

Mr. GELLMAN. The problems raised by emergency room patients or other patients who are not capable of giving consent is something that has been brought to our attention; and I think there will be an attempt to remedy that sort of situation. Is that your recommendation as well?

Mr. HUSELAND. Yes, sir.

Our larger concern is to protect the validity of our authorization. And to be valid, it appears that it would have to exist not at our locality but at the locality of the hospital.

Mr. GELLMAN. Well, if a hospital got its own authorization to disclose medical information of a subscriber to Blue Cross, that would be sufficient for their purposes and they wouldn't have to have a copy of the authorization that you have as well.

Mr. HUSELAND. If we felt that we should, ethically and practically, rely upon others to obtain our consents, that's true.

Mr. GELLMAN. It wouldn't prevent you from getting your own consent as well, according to the procedures you have already outlined.

Mr. HUSELAND. Yes, sir, I understand, but ours would not be valid—and a claim could not flow under those circumstances—until such time as we had made a copy of it and presented it to the hospital, if I understand the legislation correctly.

Mr. GELLMAN. Another question, you referred to a recent 1975 Indiana law on computerized medical records. I only got a copy of the law yesterday and haven't really had a chance to go over it in detail. But it appears to require that a patient authorization to disclose a computerized medical record is only valid for 60 days. Has that caused any problems, to date?

Mr. HUSELAND. No, it hasn't.

And I have discussed with our law department this fact, and I could only speculate the reasons. I suspect it's because that it has very limited application, that most hospitals have a noncomputerized record which they can use to provide the claims information.

Mr. GELLMAN. If more hospitals have computerized records, though, that 60-day provision would cause you a lot of trouble, wouldn't it?

Mr. HUSELAND. I am not certain I can answer that, because I don't recall the statute specifically. If the existence of a noncomputerized form or record could be used to provide that—and that's basically what is obtained from the patient at the admitting room—then it probably would not.

The thrust and the purpose of that statute was to really apply to the abuse of computers, not to the flow of the normal insurance mechanism.

Mr. GELLMAN. Thank you very much.

Mr. EVANS. Thank you, Mr. Huseland and Mr. Van Dyke. We appreciate your testimony and your responses to the questions.

Our next witness is Kathy Holbert, who is a registered nurse and has acted as coordinator of surgery at the Johnson County Hospital since 1977. She has previous nursing experience in operating rooms in New York, Florida, New Jersey, and Ohio. And prior to joining the staff of the Johnson County Hospital, Mrs. Holbert was a staff nurse and senior nurse at the cardiovascular surgical service at Riley Children's Hospital here at the IU Med Center.

Kathy, if you will proceed with your statement, please.

**STATEMENT OF KATHLEEN HOLBERT, SURGERY COORDINATOR,
JOHNSON COUNTY HOSPITAL, FRANKLIN, IND.**

Ms. HOLBERT. Good afternoon, gentlemen.

I am the surgery coordinator at Johnson County Hospital in Franklin.

I want to thank the subcommittee, and Representatives Preyer and Evans, for this opportunity to express my views on this very important bill, H.R. 2979. But I would also like to point out that I am here as a professional nurse. I am not a representative of Johnson County Hospital, and this statement reflects my own opinions.

I would like to say I am in strong agreement with the congressional report that finds that medical records are routinely made available to public and private organizations and that the individual does have the right to know what information and to whom it is being released to. Therefore, I am in support of section 111 of the bill, although I do believe that it's probably fairly easy for an individual right now to obtain a copy of his medical record, in practice, at least where I am.

I think that notification of the patient regarding his rights, as defined in section 113, would have an educational advantage to the patient. Presently, many patients view their records as something that really belongs to the institution, that they don't have a right to look at. They sort of feel like they are snooping if they open up their record while they are on their way to X-ray or something like that.

I am in general agreement with the bill. I do have some specific questions and views in regard to portions of it, and I would like to enumerate these.

On page 7, there's a definition of the term "medical record." I have some questions over whether that means any piece of material that has a patient's name on it. For instance, would this include the operating room log, the scheduling book, the daily OR schedules that are distributed that many departments need to have?

On page 10, section 112, it deals with changes made in the medical record upon a patient's request. For instance, a patient probably would need some interpretation of his record, because they are unfamiliar with medical terminology. And ex post facto revision of records is generally unethical or illegal. As a professional nurse, I can't think of any circumstances in which I would retract or change something that I had written about an event that took place with a patient. And if a patient disagreed with my statement, it would probably be reduced to my word or my version of it versus his; and I can't believe that I would change what I had written. Of course, errors in fact about statistical things like age and dates or addresses are a different kind of story.

Potential judgment decisions could result in litigation. And I submit for the record an excerpt from a medical records publication, citing the increase of an enterprising new business, called Malpractice Research Co. I have given a copy of this to the reporter, and I would like to read to you an excerpt from this.

[The complete excerpt follows:]

MALPRACTICE RESEARCH, INC.
SCREENS PATIENT RECORDS

Communications from Malpractice Research, Inc. Herndon, Va., have appeared in other states and are now surfacing in Indiana. Excerpts from their brochure: "Malpractice Research has licensed specialist physicians and surgeons available to review hospital and medical records in potential malpractice cases. . . . If you feel you or a loved one has been wronged, please use the release of records form enclosed. . . . There has been a recent federal law passed whereby your medical records must be promptly released to you, with proper written authorization.

"Malpractice Research, Inc. does not practice medicine, but refers your records to consulting physicians and surgeons who, while maintaining their anonymity, furnish you with their written consultation report on our stationery. We and our consultants do not guarantee, nor make any claims to be able to predict the outcome of any litigation or the monetary award of any settlements."

The leaflet lists 30 examples of possible malpractice. The above quotes will acquaint you with the tone of the brochure and assist you in being alert to inquiries regarding it. You may also wish to inform your medical staff about the possibility of their patients being circularized with these brochures.

If approached for records by anyone who appears to be using this type of screening, you are advised to contact the IHA legal counsel before releasing the records.

Ms. HOLBERT. This company states:

Malpractice Research has licensed specialist physicians and surgeons available to review hospital and medical records in potential malpractice cases * * * If you feel you or a loved one has been wronged, please use the release of records form enclosed * * * There has been a recent Federal law passed whereby your medical records must be promptly released to you, with proper written authorization.

I would certainly hope that businesses such as this would not inadvertently profit from this legislation. While I believe there are many patients who deserve consideration by a court of law as a result of demonstrated malpractice, I cannot support the contention that mere dissatisfaction is grounds for malpractice suits. If the availability of medical records becomes too common, it might serve to line the pockets of those who feed off patients' unhappiness and care little for justice.

I would like to refer you to section 114, on page 12. This section deals with disclosure of records only to authorized individuals, and I have a question which apparently has already been brought up about what would happen for a physician to obtain a record on his patient if perhaps he wasn't the physician in charge of the case on a previous admission or if the patient is unable to give his permission.

I can remember an incident within the past year in our own institution where the patient was under general anesthesia, having his surgery, and we had to get his old record. That was in the hospital, and I am not sure whether the surgeon was the physician from the last admission. But that could perhaps cause some problem for us. Occasionally there is no authorized personnel available, particularly on an emergency room visit.

This also raises the point of what constitutes an authorized individual and how is he to be properly identified. Finally, since the entire record is usually needed in order to extract needed information and put it in a precise, chronological order, how is this provision to be accomplished?

Section 115, on page 12, deals with the same disclosure and these release forms. And that may be impossible, in some circumstances. I think that when you are dealing with requests from outside the institution, it might be fairly easy.

Section 121, on page 13, talks about a disclosure. Down on lines 23 and 24, can an employee of the facility who has a need for the medical record in the performance of his duties get this information? And I don't see that as covering physicians, because generally physicians are not employees of the institution.

On page 19, section 127(a), it refers to a governmental authority obtaining a record pursuant to a Federal or State law. I wondered if this referred to agencies of the Government like the CIA and the FBI. I don't really understand why they should be exempt from regulations that others must follow. It would seem to me that previous sections of the bill would appear to cover circumstances involving security of life and property, health and safety.

On page 20, section 128, it deals with the CIA. Or, I interpreted this as possibly dealing with the CIA, and it seems to leave out the fact that there has to even be a statement on the chart that the CIA has this information, as is required by section 101(1) for anyone else who asks for a copy of the patient's medical record.

On page 21, section 129(a)(1)(A), it refers to a disclosure to a Government authority for the investigation of abuse in a program funded by a Government authority. As I understand it, this, to me, means that the individual's rights could be waived, broadly interpreted, by someone who wanted to investigate the misuse of, say, food stamps or something. I am not quite sure that that's a very good idea. I think that the term "government authority," on line 8, and the word "investigation," on line 9, need some clarification. And the vagueness of terms like "waste" and "abuse" would seem to give almost anyone access to the patient's record.

On page 23, section 131, it refers to a disclosure being pursuant to a subpoena. I have been told that attorneys keep papers in their offices that are marked "subpena" and signed by a county clerk, not a judge; and that often people will come to the hospital and wave this paper and say, "I have got a subpoena here. Give me the records."

In actuality, the subpoena would have to say you have to appear. It doesn't mean you have to turn over the record. However, they fail to tell you that. The way it's written, I don't know if maybe that needs some clarification.

On page 25, section 132(b)(1), on line 3, the term "auditor" is used. I wonder if that refers to PSRO. If so, it would seem to give the Secretary of Health, Education, and Welfare authority to prescribe possibly unwieldy security standards in an institution.

On page 27, section 141(c)(3)(C), I wonder who is the person, although it may seem to be the court a little bit above that. It says "if the court finds," but it talks about the Government's need for the record in the inquiry outweighing the individual's privacy interest. But I am a little unclear as to who would determine this.

On page 28, section 142, it refers to a patient or an individual being able to quash a subpoena. I don't quite understand how an individual could do this, if he doesn't have any idea that the subpoena is there and that they have taken his record; because as I understand section 131, the consent of the individual may not be necessary to obtain that information.

In summary, I would like to say I have some reservations about the proposed legislation. But, in general, I am favorably disposed toward it, because I think it would give the individual a great deal more say in his medical records which do contain a great amount of information about him.

Thank you for allowing me to express my views.

Mr. EVANS. Thank you, Mrs. Holbert. Certainly it was a most perceptive analysis and critique of the bill that you have presented to the subcommittee.

I was most interested in your comment on page 1, where you state: "Presently, many patients view their records as something that belongs to an institution, and to which they have no right."

I think also the comment that you made on page 3 in regards to section 127(a) on page 19 of the bill, referring to certain government agencies, that perhaps the chairman might join me in observing that I think it would have been most interesting if Mrs. Holbert had had an opportunity to be in Washington when we heard from the Director of the Secret Service in regards to his testimony

and feelings in regard to the need of that particular bureau for pretty much unlimited access to patient information.

Also, a number of the questions that you have raised are ones that have been considered while others have not been addressed. But in later drafts of the bill, I am sure the subcommittee will correct and further clarify the answers to some of the questions which you raised.

I thought it also would be interesting, for you to comment on the results of a nationwide opinion research survey of attitudes toward privacy recently conducted and released before our subcommittee by Lou Harris & Associates. When asked the question, "Do you think people who want to should have the legal right to see their medical records held by their personal doctor, clinic, or hospital; or do you not think that should be the right of individuals?" Of the public surveyed, some 1,509 individuals across this Nation, 91 percent said that they should have the right to see the records held by their personal doctor; and the same number, 91 percent, indicated that they should have the right to see the records in the possession of clinics or hospitals.

I would like to ask one or two questions. Do you believe that patients today are more reluctant to share information with their doctors, because of the fear that information may be used against them sometime in the future or because possibly it may end up in a computer somewhere? Have you noticed any attitudinal change?

Ms. HOLBERT. No, I really haven't. I can't say, because of the clinical area that I work in. I don't have that much exposure to it, because in the operating room you generally don't get into discussions with patients and the physicians, sitting down talking.

But I have not experienced that they are reluctant to now, any more than they ever were.

Mr. EVANS. The bill before us, one of the two bills at least, H.R. 2979, permits disclosure of a medical record to a hospital employee who has a need for the record in the performance of his or her duties. Do you think that this is a realistic standard that we have set forth here, or is there any practical way for a hospital to restrict access once a record has gone beyond the record room itself?

Ms. HOLBERT. I think it's fairly realistic. I think it's very necessary.

It's true, I think it would be easy to say who could have the record, to take it out of medical records, and determine whether they really needed it. I think, once it left there, you have to rely, as we have in the past, upon that person's professional responsibilities and their own ethics on what they do with that.

Our own medical records department watches the records pretty closely. You would not be able to, say, take 5 or 10 patients' records and keep them for a week and no one ask you, "What have you done with them? Why aren't they back?" You know, you can't leave them around on your desk and not under lock and key.

Does that answer your question?

Mr. EVANS. Yes, I think so.

Chairman Preyer.

Mr. PREYER. Thank you.

You hold a position, I see, of surgery coordinator at the Johnson County Hospital. I think, from reading your critique, anytime you want to go into the legal profession you would be a very fine Philadelphia lawyer, too.

As an operating room surgery coordinator, are you ever asked by another hospital or have you ever had to seek from another hospital information on an emergency basis about a patient?

Ms. HOLBERT. No, I never have.

Mr. PREYER. About another patient's records?

Ms. HOLBERT. I never have.

Mr. PREYER. As far as you know, it has never been a problem in the operating room, of hospitals exchanging records on an emergency basis.

Ms. HOLBERT. No.

Generally, if the physician wants a specific piece of information, he may get on the telephone and talk to another physician about that patient. But as a nurse, I have never been asked to intervene in it before.

Mr. PREYER. So occasionally a physician will talk to another physician on the telephone.

Ms. HOLBERT. Yes, particularly in the emergency rooms. If a patient comes into an emergency room and they have to be transferred to another hospital, because where they have been admitted there are not facilities to take care of them, they will call on the telephone to the hospital that they are sending the patient to and tell them about their injuries and a little bit of information.

Mr. PREYER. Does a physician ever call another hospital, rather than another physician, and ask for information on an emergency basis of that sort?

Ms. HOLBERT. I don't know.

Mr. PREYER. Is it almost always doctor to doctor?

Ms. HOLBERT. Generally so, in my experience.

Mr. PREYER. I was just curious. I hope there is never any difficulty in exchanging that sort of information. You do wonder what procedures there might be to make sure that a person is who he claims he is. If a doctor is calling a doctor he knows, there is no problem. But if you, as surgery coordinator, ask another hospital someplace for information on the telephone, on an emergency basis, I was just wondering how it could be sure that the call was legitimate and that it wasn't Ace Private Detective Agency calling.

Have you, as a surgery coordinator, ever been asked for any information or records by police officials or by the FBI?

Ms. HOLBERT. No.

Mr. PREYER. I take it, in your position, you simply don't hold the role in which you are ever asked by anyone other than a hospital employee about records.

Ms. HOLBERT. Not by someone in authority. I happen to live in a small town, where over the bridge table people know who has been in and out of the hospital; and you sort of get into those circumstances.

Mr. PREYER. What sort of records do you keep in the emergency room? Are you required to keep certain records in the emergency room, or are those records kept as part of the general medical records in the hospital?

Ms. HOLBERT. They are classified as outpatient records, and they are kept in separate files so that—for a certain period of time. Then if it's an old outpatient record, it may be put in with the patient's chart, but there is not a whole lot of information. It's usually just one piece of paper, the emergency room record.

Mr. PREYER. And they are never disclosed outside, as far as you know. They are simply sent down to the office and put in with the other outpatient records.

Ms. HOLBERT. Yes.

Mr. PREYER. Thank you.

Mr. EVANS. Congressman Kindness.

Mr. KINDNESS. Thank you.

There's one area that—I first certainly want to join in complimenting you on your analysis of the bill today, because you made some very salient points. But there is one area that I would like to solicit your thoughts on, and that has to do with the child patient, minor patient, and access to information about the child's condition, treatment and so on.

Who should have access to that information and under what circumstances, generally, as you see it? The parent, perhaps a close friend under some circumstances, who may be practically speaking in charge of that child's welfare at the moment, or other persons that may be close in some way? Are you aware of problems arising in this area, even as things stand today, and how that might be further somewhat complicated by the legislation we are considering?

Ms. HOLBERT. Are you referring to an authorized individual, releasing information on the child, or who should know about what is going on with the child?

Mr. KINDNESS. Who should know what's going on with the child and, let's say, should have access to the record. Also, perhaps going a bit beyond that, there's another area to consider; and that's when you get up into the adolescent years. What sort of access ought there to be on the part of the parent to the medical record, in cases that might involve, for example, records relating to an abortion or to possibly another health care situation, such as birth control treatment or what have you? Are there any observations that you have in that area that you would care to share with us?

Ms. HOLBERT. I hadn't thought about those particular ramifications.

In terms of thinking of an ill, small child, I certainly would be in agreement that the parent should have the same rights of access as the individual adult patient would have to his own record. As a mother and as a professional nurse, I would certainly want access to my child's record for future reference, if we moved away. And I can, and there's millions of nurses and physicians who could understand their own records, and even medical records people. And I would like access to read that, so that I know what's going on with my child.

I would assume there would have to be some way of protecting the adolescent child's rights of privacy, so that he still has the right to get birth control pills or have an abortion, without having to have his parent's consent as he now can. You know, perhaps something that if he has given his own permission to do that, or to

get those pills or to have that abortion, then that part of the record is not included in the parts of the record that the parent might have access to, if the bill was written that way.

Am I making myself clear?

Mr. KINDNESS. Yes.

It is a difficult area to consider, and I wanted to get your thoughts. And they are perceptive thoughts, thank you.

Mr. EVANS. Thank you, very much.

Ms. HOLBERT. Thank you.

[Additional comments from Ms. Holbert follow:]

AUG 21 1979

510 N. Main St.
Franklin, Ind. 46131
August 20, 1979

Dear Representative Pryor,

I wish to thank you for the opportunity to express my views on H.R. 2979, Saturday, July 14, 1979.

I was, I confess, a bit overwhelmed at first by all the " credentials " I was surrounded by, but as the hearing progressed I was glad to be there to represent the " common man's " viewpoint. I hope the committee will solicit more opinions from those who do not represent associations or institutions. These institutions have a vested interest in protecting their own investments and systems.

I read with interest the other testimonies, and would like to make some comments for your consideration.

In the statement from the Indiana Health Care Assoc. page 3, paragraph 2, there is a claim that new legislation and regulations would place " another wedge " between physicians and their patients. It further states that all activities undertaken by patients while in their facilities are ordered by the physician.

This may be the case in nursing homes. I have never worked in one so I can not dispute this. However, in general hospital practice there are many health care professionals who exercise a great deal of autonomy from the physician in caring for the patient. Today's nurse practices his or her own profession of nursing, and as such carries out many activities that are not specifically ordered by a physician. Nurses are no longer simply " handmaidens " of the physicians who simply implement his or her orders. In a normal hospitalization, a patient may be cared for by a diverse number of health care professionals, trained specifically to practice their specialty, among these

physical and respiratory therapists. A physician may request one of these specialists to see his patient but the precise treatment is often left to the discretion of the professional staff person being utilized.

There is a recent trend in nursing, an experiment whereby a group of nurses organizes an operating room and then contracts with surgeons who wish their services for a particular operation and patient.

As a surgery coordinator, I expect that my staff practice nursing of the surgical patient according to the standards set by our own professional organization, the Association of Operating Room Nurses. The routines and procedures we carry out during the course of an operative procedure are not defined by surgeons. They are defined by surgical nurses. Doctors practice medicine. Nurses practice nursing.

I would further like to state that it is the goal of medical professionals to involve the patient in the care of his own body. If this goal is to met it will be necessary to educate the public more fully. Therefore, this bill could greatly enhance their awareness of the necessity and benefit of becoming more familiar with medical terminology. In our very mobile society it would be beneficial if patients could carry with them, even if only in their heads, some knowledge concerning previous health problems, and hospitalizations.

Again, may I thank you for the opportunity of expressing my views. If I may be of any further assistance to you or your committee, please feel free to contact me.

Sincerely,

Kathleen M. Holbert
Kathleen M. Holbert, R.N.

cc Rep. Dave Evans

Mr. EVANS. Our next witness is Dennis Dawes, who is the administrator of the Hendricks County Hospital. Prior to his position there, he was the assistant administrator and also served as a health educator for the Indiana State Board of Health and director of field services at Indiana Health Careers, Inc. He is president of the greater Indianapolis hospital district and is a member of the American College of Hospital Administrators and the Indiana Hospital Association, Cummins Mental Health Clinic and the Indiana Hospital Association's Council on Health Care Delivery.

Welcome, Mr. Dawes. And, if you would identify Mr. Render and his position with the hospital association for the committee's record, we would appreciate it; and please proceed.

STATEMENT OF DENNIS W. DAWES, ADMINISTRATOR, HENDRICKS COUNTY HOSPITAL, DANVILLE, IND.; ACCOMPANIED BY JOHN RENDER, GENERAL COUNSEL TO INDIANA HOSPITAL ASSOCIATION

Mr. DAWES. Thank you.

With me is Mr. John Render, who is general counsel to the Indiana Hospital Association.

Mr. Chairman and committee members, I am Dennis Dawes, administrator of Hendricks County Hospital, Danville, Ind. It is a pleasure for me to address the subcommittee today on behalf of the proposed legislation, H.R. 2979.

The Indiana Hospital Association represents 114 short term acute care hospitals in the State, as well as a number of specialty and teaching hospitals and many personal members. We do appreciate the opportunity to participate in these hearings concerning medical record privacy.

The position of the Indiana Hospital Association regarding privacy of medical records:

Historically, IHA and its member hospitals have considered hospital patient medical records to be privileged and confidential documents which, because of their content, must be protected and preserved by adequate system to insure disclosure upon appropriate authorization or other legal process. Specifically, it has been our position that medical records of patients should only be released in whole or in part, or examined, upon authorization of the patient, his legal guardian or other lawful representative, or upon subpoena or court order issued by a court of competent jurisdiction. Absent such written authorization or appropriate judicial process, it is the position of the Indiana Hospital Association and its member hospitals that contents of medical records should not be disclosed to third parties.

While there is no Indiana statute specifically delineating the conditions for release or examination of medical records generally, nor is there any definitive Indiana case law concerning the general subject, we believe the general principle we have described herein should govern or handling of medical records and further that such principle does in fact protect the rights of individual patients as well as permit legitimate disclosures to third parties where they have obtained patient authorization or intervention of a court of competent jurisdiction. In other words, we believe that it is important that any legislative enactment carefully balance the privacy of

individual patients with the legitimate and lawful needs of third parties to obtain information contained in medical records.

Concerning the general subject of medical records, it is our position that the hospital medical record is in fact the property of the hospital and is owned by the hospital and may be used for legitimate internal purposes. However, although the record is owned by the hospital, it is our position that the patient has a legitimate and appropriate right to examine or obtain copies of his or her own medical record upon appropriate inquiry and authorization. Again, although there is no specific definitive Indiana law concerning these two latter principles, we are confident that they are an accurate reflection of the status of medical records in Indiana from a judicial standpoint.

Some further comments on H.R. 2979:

We wish to express our general support of many of the principles set out in the bill. In particular, section 2, which contains the findings and purposes, announces several points with which we are wholeheartedly in agreement, particularly as it relates to the absolute right of privacy of individuals being a person and fundamental right protected by the Constitution of the United States. Furthermore, we believe that an individual right to privacy must be balanced against legitimate needs of public and private organizations for access to such information.

We likewise believe that the provisions found in section 114, relating to disclosure, are sound and that hospitals should not disclose medical record information except under conditions therein set out. Likewise, the authorization for disclosure found in section 115 contains very sound fundamental principles relating to the conditions for a valid authorization for release of records; and we are wholly supportive of that section.

Similarly in section 121 regarding disclosure of medical records without specific authorization, it is well-founded and contains appropriate exceptions to the general principle relating to authorization for internal hospital use and other legitimate uses as set out in the following sections contained in part C. Further, we do applaud the author and the subcommittee for the provisions contained in section 152, wherein criminal penalties are established for persons obtaining medical records through false pretenses. It is our understanding that such provision may clarify confusion or uncertainty in several states as to whether unauthorized retrieval of medical records constitutes a crime or unlawful offense under existing statutory law.

In summary therefore, many of the provisions of the bill, including several sections not herein cited, are sound, reasonable provisions relating to privacy, authorizations, disclosure and similar matters, all with regard to the subject of the institutional medical record.

However, the Indiana Hospital Association does have some concern about specific sections of the bill, particularly in the area of correction of medical records, recordkeeping requirements, security standards, and Federal supremacy. For example, section 113 requires that a medical facility shall provide an individual with written notice of recordkeeping practices when the facility first provides services to the individual. We are concerned about the

administrative burden imposed by this section upon health care facilities.

Further, we are not at all sure of the necessity for such section so long as the health care facility is required to abide by certain disclosure requirements or procedures pursuant to Federal or State law; that is, the necessity for individually informing patients concerning recordkeeping practices seems unnecessary as long as there is compliance, and this seems to impose a considerable administrative burden on the institution.

Concerning section 112 relating to the correction of medical records, we have grave concern about this particular section since we are concerned that it would foster needless and unproductive bickering, confrontation, and disagreement between hospital patients and hospitals. Further, since medical records contain in part judgmental notations, as distinct from factual occurrences, it is always possible that there may be disagreements with judgmental evaluations resulting in innumerable conflicts regarding the so-called correction of medical records. However, our comments regarding this section should not be interpreted to mean that we do not wish to maintain accurate medical records and should not make needed corrections where there is clearly erroneous information in the medical record. We are more concerned about the procedures set out in section 112 than in the substance contained therein.

Concerning section 132, we are particularly disturbed about this section since the Secretary of Health, Education, and Welfare is therein required to prescribe security standards with respect to the use and maintenance of identifiable medical record information. We are concerned primarily because of the undoubted considerable increase in recordkeeping and other administrative compliance that will be required.

Our previous experience as a hospital industry in dealing with Federal regulation has not been a pleasant experience, and we would envision nothing different with reference to these proposed standards, rules and regulations. Further, it has been our experience that increased regulation in the hospital industry by the Federal Government is always costly, often unproductive, and frequently disruptive. With the increasing public and private concern for containing health care costs, it is essential that the regulatory process be a facilitator for, and a burden to, the use of hospitals in this country.

In our judgment, this will require a significant improvement in the current Federal regulatory process to make it a more responsive process and more reflective of the congressional intent, and particularly more cost effective.

Finally, section 102 concerns us considerably since that section essentially provides for Federal preemption in the area of medical records privacy and disclosure. We believe that, to the extent this subject matter requires legislative initiative, such initiative should occur on the state level as opposed to the Federal level. This is not to suggest that the Federal Government, and specifically the Congress of the United States, does not have a legitimate interest in personal privacy, but only is to suggest that the States may be more capable of responding to specific privacy issues particularly as it relates to health care.

Therefore, we would urge in your consideration of H.R. 2979 that to the extent State law addresses adequately the subject of privacy of medical records, that H.R. 2979 would not supersede existing State law.

In summary, we again wish to thank you for your courtesy in permitting us to testify and express our opinions regarding the necessity of preserving medical records in a secure manner so as to ensure that individuals may seek hospital treatment without that fact being communicated to third parties in general, unless communication is authorized specifically.

And we also pledge to work in cooperation with you, in the subcommittee, in any way possible.

Thank you.

Mr. EVANS. Thank you, Mr. Dawes.

I am interested in your comments here on the administrative burden and the costs involved with the legislation that we are considering. The experience, I think, that has been shared with this committee in the past, at least in regards to Federal hospitals, is that very few patients seek access to their information; and the cost of administratively supplying that information in that small percentage of cases also has been small.

I guess what you are really telling us is that you are perhaps more concerned with the cost at the other end, when the patient is coming in, in terms of supplying that patient with information and written notification. Where do you see the heaviest cost burden that potentially might be associated with this legislation falling?

Mr. DAWES. I think you are correct in stating that currently the requests for the individual patient to receive, say, a complete copy of their medical record, et cetera, is probably small. If legislation like this was enacted and it became much more of a concern to patients to request complete copies and in fact a hospital was required upon initial treatment to go give a patient as much information as possible or at least report to them how we would administratively go about giving them that information, then that is where a lot of the cost would be incurred and then later on when we would have to supply them with all of that necessary information.

Mr. EVANS. Do you know of any hospitals that have decided against patient access because of costs involved?

Mr. DAWES. No, I don't.

Mr. EVANS. You are not aware of any here in the State of Indiana, Mr. Render?

Mr. RENDER. No, sir.

Mr. EVANS. What is the practice of Indiana hospitals with regard to patient authorizations? Specifically when will an Indiana hospital make a disclosure without written consent?

Mr. DAWES. Without specific written consent from the patient, we will only make disclosure of medical record information upon a subpoena from a court or a competent or judicial body. That is basically the only time, other than obtaining consent from the patient in writing, to release their information.

Mr. EVANS. So you are including law enforcement personnel, for example, either local law enforcement, Secret Service, whatever.

You would require them to have a court subpoena in order to release that information.

Mr. DAWES. Yes.

John might want to comment on that further.

Mr. RENDER. Mr. Evans, there are a couple of specific statutory exceptions to that in Indiana, which is common in many States. For example, we have a statute regarding gunshot wounds and pointed instrument wounds. And by Indiana State law, we are compelled to provide information to law enforcement agencies when a patient is admitted to the hospital or treated at the hospital for one of those types of defects.

Child abuse is another area. The previous witness testified in response to a question by Mr. Kindness regarding child abuse. We have an extensive child abuse and neglect statute in Indiana, which requires us to, one, notify either the appropriate law enforcement agency or what is called the child protective agency of each county regarding suspected child abuse. But further, we also have to provide sufficient medical record information.

So there are two or three statutory exceptions by which we are compelled to provide information when a certain occurrence occurs.

Mr. EVANS. So if the Director of the Secret Service instructed one of his agents to visit your facility or Cummins Mental Health Clinic, specifically to request information regarding potential threats against the life of the President or some other Government official, if you did not have either a court subpoena or if this information was not covered under one of the State statutes, that information would not then be released. Is that correct?

Mr. RENDER. I would have to basically say yes, unless it was covered by a State statute. Or, there are certain Federal statutes which are preemptive in nature, you are undoubtedly aware.

For example, the IRS, there's an obscure section of the Internal Revenue Code—perhaps not obscure—but it permits the Internal Revenue Service under certain circumstances to have direct access to certain kinds of information.

But generally speaking, this has come up before. Law enforcement agencies, both local and national, have come to individual hospitals, saying we want to obtain certain information about a patient we think was treated and that sort of thing. Generally speaking, we refuse those requests, although we try to indicate to the law enforcement people that we want to cooperate with them, that we want to assist in appropriate law enforcement, but we can't do it by violating patient records. We normally request that they obtain a court order from the Federal district court or a subpoena from a Federal district court, upon the production of which we will provide the information.

Mr. EVANS. I guess according to what we have heard from Director Knight, Indiana perhaps falls a little closer to Massachusetts than to Texas.

Chairman Preyer.

Mr. PREYER. Thank you.

I appreciate your testimony very much. I can understand, being in the hospital business, how you feel a little gun shy about any sort of proposed Federal regulation. You indicated that your experience with that hasn't been too good in the past.

One of the points that I think Congressman Evans was making was that as far as this business of the law allowing access of patients to their own records, there is a fear that that would impose a great administrative burden, because almost every patient—or many patients—would ask for access to their record. That hasn't proved to be the case in the testimony we have from.

We have heard from a lot of the Federal hospitals which operate now under a law permitting patient access. They have told us, for example, that the number of requests has been something like 1 or 2 percent; so that if you had a 100-bed hospital that would be, say, 5 or 10 requests a year. That would not be a burden. I think we would all agree. If permitting patient access to their records didn't amount to any more than 5 or 10 requests for a 100-bed hospital a year, that wouldn't be much of an administrative burden.

But I guess what you are concerned about is as the idea becomes popularized, as patients know they have access to their records, will that suddenly jump to where it becomes a real administrative burden. My recollection on that is that at some hospitals—some of the witnesses testified from Federal hospitals, St. Elizabeth, that they notify the patients when they come in that they have access to their records; and they just haven't found that much interest.

I don't know whether that would prove to be the case nationwide or not, particularly as we begin to get more interested in the question of privacy around the country. But so far, at least, the experience on if you say to patients, "You have the right to have access to your records," it has not resulted in a great flood of requests. I can see how hospitals would be very concerned over the cost and over the administrative burden if it did. It looks like it won't, at least as far as the present experience goes.

Also on the question of whether any sort of bill would involve a great deal of new restrictions that involve new types of internal controls that the hospital would have to set up, you just gave a long account of laws requiring you to do these things. I think almost all hospitals today maintain some pretty elaborate controls over who can and who can't use their records. You have given some examples of how you restrict access in your hospital.

I wonder if anything under this bill that's proposed would really involve setting up any new types of internal controls or whether it might just involve some minor adjustments of existing controls that are already set up. At least that is the hope, because I think we all share your concern that a whole lot of regulatory redtape isn't the way to go at it.

Do you think, on that point, that any significant new costs would be incurred by hospitals to set up new types of audit controls under either of the two proposed bills we have discussed here? Or would it involve fairly minor adjustments to your present system?

MR. DAWES. We would hope the latter; and I think it would depend on probably how much latitude is given to whomever is prescribed as writing the detail of regulations to outline what the process would be for us to carry that out.

If we were allowed our own individual efforts, it would probably be minimal. If, say for instance, the Secretary of Health, Education, and Welfare was allowed a lot of latitude to write considerable detailed regulations, then, for instance, we would probably

consider that it would be pretty costly. To make minor adjustments now would not be very costly, and we could handle that, internally within any hospital and probably within each State.

Mr. PREYER. I think Congress has become far more concerned than it has been in the past years on that same question. I think the thrust of anything that Congress might do on it would certainly be to allow you to make adjustments and not HEW.

We had a vote on this last week, I guess it was——

Mr. DAWES. Yes.

Mr. PREYER. On the SHUR amendments—we thought we were asking them to come in with a uniform reporting system in which the figures would be standardized and HEW came back with a uniform accounting system which would require all the hospitals to change the whole accounting system. And you know that better than I do.

Well, I can understand your fear from your experience on that. The purpose of this bill is certainly not to bring about that kind of thing. We were thinking in terms of a few minor adjustments which would solve the problems here.

Let me just ask, finally, on the question you raise on page 2. You stated that it's your position that hospital medical records are in fact the property of the hospital and owned by the hospital; but though owned by the hospital, the patient has an appropriate right to examine them. We are getting into some legal problems there. I think we both have the same understanding of what we want. The hospitals are not a place where the patient can go and take his record and go off with it. The records are the hospital's. But it isn't really quite total ownership or control, because the patient does have access to it and we are limiting what the hospital can do with it.

We got into some trouble in banking laws. The Supreme Court recently came out and said the bank records are the property of the bank and not the depositors. As a result, the bank said, well, anybody that wants to look at them, they are our records and we'll let them look at them, private investigators, credit companies, FBI, anybody that would come in and say, can I see X's deposits, can I see X's bank records. These records are very intimate personal things, because you can reconstruct a person's life pretty much from his bank records, very much as you can reconstruct a lot of it from his medical records.

Because of that decision, many banks were allowing a lot of people to see what we all thought, when we wrote a check, was a private matter. But it turned out it wasn't so private after all. So Congress passed a law, the last session, dealing with privacy of bank records. We don't want that kind of abuse to happen in medical records; and I don't think we want the hospitals or institutions to assume hospital records are their property, in that same sense that the banks said that the bank records are bank property.

I wonder if you see any advantages. You pointed out that although there is no specific definitive Indiana law concerning these two principles that we have been discussing, we are confident that they are an accurate reflection of the status of medical records in Indiana from a judicial standpoint; and I am sure that's right. But I wonder if you see any virtue in a law which makes clear, maybe

for the first time, exactly what types of disclosure a hospital can make of its records without risk of legal liability. We are assuming these principles are the law, but we are not too sure. And the Supreme Court could come along with a *Miller* case, like they did in the banking business, and apply it to the hospital.

Is there any virtue in trying to clarify what is the law there, making sure what you as a hospital administrator can and cannot disclose?

Mr. DAWES. I might let Mr. Render respond to that briefly, and then I might comment, too.

Mr. RENDER. Mr. Chairman, if I may briefly, the 1975 law that was alluded to previously was the one we wrote, the computerized medical record bill. We found a need to introduce that piece of legislation which addresses a number of these issues: the vintage of the authorization, the audit controls—mainly because we were concerned about computer abuse. Well, as it has turned out in the last 4 years, there is such a limited application of computerized medical records in Indiana that it really has no efficacy in Indiana.

But we have not found a similar need to have a general bill or statute on medical records primarily because, quite honestly, we have not experienced any significant or even insignificant problem in Indiana with unauthorized disclosure. To be quite honest with the subcommittee, our major problem in medical records—and we do get a fair number of phone calls and inquiries on the subject—is from third parties attempting to retrieve information. And in fact, we have a number of calls from members of the bar association, complaining that the medical record administrators will not give them copies of the record even when they have valid authorizations. And I have to be very honest again, that that does occur.

I think our medical record administrators in Indiana have been so indoctrinated, if I may use the term—because I think we helped them in that indoctrination—to preserve the confidentiality of that record, that any problems we have are in underexposure as opposed to overexposure. And it has reached such a magnitude that we are meeting with the bar association currently, trying to work out a uniform system for disclosure of information and what the authorization has to look like and so forth.

That's a long-winded answer, Mr. Chairman, but we have not found the need to legislatively regulate the subject in Indiana.

Mr. PREYER. I think that's a very good answer and also an answer that I think not many States could give in the country. Most generally, the problem is on the other side. I congratulate you for the care with which you approach this whole problem of privacy of medical records.

Mr. DAWES. If I could make one other brief comment, and that is concerning, say, the patient wanting to see their own record while they are under care within the institution by their physician, that that could also present some problems; and therefore, we also guard that equally closely. Although if a patient does want to see their record in conjunction with their physician, et cetera, we will certainly do that.

But I think you can understand that it would impose some potential compounding problems if the physician, say, was calling in another consultant in the case as well and they were looking for

something in specific and had not found it yet; and it could cause undue hardship on the patient, their family, et cetera. So these are things that we are also concerned about with the legislation.

Mr. PREYER. Thank you. You have made a good point.

Mr. EVANS. Congressman Kindness?

Mr. KINDNESS. I realize there's a time constraint we are working against here, but I would just like to ask one question in the area of correction of medical records. Are there somewhat standard procedures that are followed at the present time in Indiana hospitals, or in your hospital, with respect to the correction of a patient's record if the patient indicates that there is some error, whether factual or judgmental, for that matter?

And while you are at it, in responding to that, is there taken into account in any such procedure the fact that sometimes patients want corrections in their records so that they will qualify for disability benefits and other such benefits, which is a real problem to deal with in this area, as I see it.

Mr. DAWES. I can't say every hospital, but I would say most every hospital would have a medical records committee, composed of physicians and other ancillary personnel, including the medical records administrator who is the overseer of the medical records. That committee would review the content of the medical record within the hospital, the appropriateness of information in the medical record. And I would say that we do have a way of overseeing the content and the quality of the record, what is going into the record; and if there is a physician abuser of not putting adequate information in the record, that committee would also oversee that. There are other processes we have of auditing, medical auditing, not financial auditing, of records, that would also document a physician or ancillary personnel, who will be an employee of the hospital, as to the content of information within the record.

So there are ways that every hospital has of, I feel, adequately insuring the content of the medical record and of seeing that it is of high quality. We are also reviewed on the quality of the information within the medical records by the Joint Commission on Accreditation of Hospitals. So I feel that there is assurance there of the quality and content within the medical record and also ways of allowing for errors in the record to be corrected by the same process, either the medical auditing process or the medical records committee that would oversee that.

The other question of a patient wanting information changed so that they could collect on some insurance, et cetera, I would say at times that possibly could be the case; and therefore, we could have a compounding issue if more and more patients requested that and wanted information changed, because of the way around of collecting on some insurance, be it disability or whatever. That could become a problem. I don't think it is a major problem at this point, but it could become more of a problem.

Mr. KINDNESS. Thank you.

Mr. EVANS. Thank you very much, Mr. Dawes and Mr. Render.

We are a little after 4 o'clock at this point. We need to bring this hearing to a close no later than 4:45, and we still have three witnesses that we want to hear from. So I would like to ask the remaining witnesses, if they can, to briefly summarize their state-

ments. That would be most helpful. We have copies of the statements, have gone over them. And if there are questions to be asked, I think it would facilitate matters if you could summarize your statements at this point.

I would like to call Bob Norman, who is the administrator of the Heritage House Convalescent Center in Shelbyville, Ind., and also president of the Indiana Health Care Association. His past and current involvement in other health care and civic organizations include chairman of the Legal Coordinating Committee and Comprehensive Health Planning Committee of the American Health Care Association, president of the Shelby County Comprehensive Health Planning Council, chairman of Blue Cross/Blue Shield Joint Provider Relations Committee, and a member of the Indiana Department of Public Welfare Claims Review Committee.

Bob, if you would introduce your attractive associate here for the record, why, we would appreciate it.

STATEMENT OF C. ROBERT NORMAN, ADMINISTRATOR, HERITAGE HOUSE CONVALESCENT CENTER, SHELBYVILLE, IND., ON BEHALF OF THE INDIANA HEALTH CARE ASSOCIATION; ACCOMPANIED BY JANET COERS, ADMINISTRATOR, HERITAGE HOUSE CHILDREN'S CENTER, SHELBYVILLE, IND.

Mr. NORMAN. This is Janet Coers; she's an accredited records technician. She's a member of both the Indiana American Medical Records Association; she's also the administrator of the Heritage House Children's Center in Shelbyville.

Mr. EVANS. Please proceed.

Mr. NORMAN. OK, fine.

Mr. Chairman and members of the subcommittee, I am C. Robert Norman, administrator of the Heritage House Convalescent Center in Shelbyville, Ind. I am testifying here today on behalf of the Indiana Health Care Association, for which I served as president in 1970, 1971, 1974 and 1975; and I am currently serving as a member of the board of directors.

The Indiana Health Care Association is a nonprofit trade organization representing 273 licensed long-term health care facilities, with more than 26,000 long-term care beds in the State of Indiana. Our association is one of the oldest nursing home associations in the Nation and was the founding member of the American Health Care Association, the largest federation of long-term health care facilities in the country.

I would first like to welcome you to Indiana and to commend you and the subcommittee for affording citizens of the Midwest a first-hand opportunity to participate in and observe the legislative process.

The proposed legislation you are considering today would affect virtually all licensed health care facilities in Indiana, since all but a few are certified to provide services to recipients of medicare and/or medicaid. As an association, we endorse in principle the concept of privacy of medical records.

Generally speaking, however, in the long-term health care setting, we do not believe the best interest of the patient is served by disclosing his total patient record to him. We feel that the physician population of Indiana would also agree with this statement.

The average patient of a nursing home does not have sufficient knowledge of medical terminology or professional practices to interpret his or her medical record correctly. Indeed, I suspect that few of us would be able to read our medical record and understand correctly what happened or is happening to us.

In addition, we feel current laws, both Federal and State, and regulations governing operations of skilled and intermediate nursing facilities adequately protect the privacy of medical records. There is, however, some confusion as to the interpretation of existing regulations, especially regarding to what extent and under what conditions the medical record can be released.

The Secretary of HEW has the authority to promulgate regulations in this area, and it is our association's position that he use his authority to clarify the regulations already in place for our facilities.

Mr. Chairman, the biggest problem nursing homes have today is, in our judgment, the position we have been forced to take between the patient and his attending physician. Quite frankly, we view any new legislation or regulation as placing another wedge between physicians and their patients in our facilities. Although H.R. 2979 would not affect the physicians in their private offices, it does affect individual practitioners in our facilities.

It affects them because, when we disclose a medical record, we are disclosing what they have written. As a party to the record, they incur a point of liability when that record is released. Nothing takes place in a nursing home that is not ordered by the attending physician. Even the types of recreational activities our residents can participate in is ordered by the physician. As a practical matter, the nursing home will at least notify the physician if a request for the record is received. And in some cases, the facility will not routinely release a record unless the physician concurs, except in the case of a subpoena.

Section 111 of the bill states that the "medical care facility may deny an individual the right to inspect a medical record if it determines that the inspection might reasonably be expected to cause sufficient harm to the individual so as to outweigh the desirability of permitting access." What I am saying is that no one short of the attending physician can make this determination. We are, therefore, involving the individual practitioner and are also involving the doctor-patient relationship. The proposed legislation does allow for someone else to be named to review the record, section 111, but we trust the purpose of some other party reviewing the record is to ultimately inform the patient of its contents and thereby circumventing the intention of the denial in the first place.

In the conditions of participation for long-term health care facilities, it states that the responsibility of informing the patient of his condition lies with the doctor. I quote from 42 CFR 442.311:

Each resident must be fully informed by a physician of his health and medical condition unless the physician decides that informing the resident is medically contraindicated; (2) If the physician decides that informing the resident of his health and medical condition is medically contraindicated, the physician must document this decision in the resident's record.

In summary thus far, we as nursing home providers agree that medical records should not be given to just anyone who wants

them and that the patient should have some say about who receives them. But also, however, we believe that even the patient should not see his medical record whenever requested, unless the attending physician concurs.

I think the real problem will develop if patients are allowed to correct their medical records. As I stated earlier, the ability of a layman to read the medical chart and truly understand it is at best limited; but to give the patient the latitude to suggest or demand corrections is, we believe, going to reduce not only what professionals write in the chart, but would truly restrict the professionals' ability to practice their trade. Ignorance is a dangerous thing and a little knowledge is worse yet.

I can see some of our residents reading their charts and disputing everything written. Some laymen would even become upset if they would read the word "negative" which would appear next to a test result, since to most people "negative" is bad. Mr. Chairman, we can see daily situations where even the most alert, intelligent patients in our facilities would have problems correctly interpreting their charts.

Another consideration is the cost impact of the legislation. We have estimated that it would require a half-time employee, 20 hours per week, in the average Indiana facility, approximately 100 beds, to comply with the provisions of either bill. I have estimated the cost of just this labor at \$1,877,000 for Indiana facilities alone. In addition, section 151 of the bill requires that facilities provide both assurances and evidence, from time to time, of substantial compliance. Our experience has shown that what is considered assurances and evidence will amount to reams of paper, which in essence say "we did it."

We can understand and support the contention that modern technology has enabled enormous amounts of information about each of us to be disclosed to other people without our knowledge. To the extent that the purpose of these proposed laws contradict this trend is laudable. To the extent, however, that these bills implement a system of recordkeeping, checking and double checking to prevent misuse of medical records is, we feel, going to create practical problems in long-term health care facilities which will far outweigh any benefits.

I believe current statutes and regulatory authority exists which, with some simple clarification, will solve most of the situations encountered in long-term health care facilities. Frankly, we do not feel there are a great number of problems dealing with release of medical records in our nursing homes. If a major problem does exist, it is, as I said, in the continual erosion of the doctor-patient relationship caused by the enactment of regulations which create an atmosphere of patient versus doctor in our health care delivery system.

Thank you, and I will be happy to answer any questions.

Mr. PREYER. Thank you. We appreciate your testimony. From what you testified, from the nursing home standpoint, there are not a great number of problems in that area. I also believe that your evaluation of these matters is probably accurate, as far as the testimony we know about.

I think some of your concerns there about correction of records, for example, might be excessive. They are certainly beyond what we have in mind in the bill, because we appreciate that patients shouldn't be allowed to correct the medical aspects of this record; and I think what is in mind there are more gross errors of simple facts and misstatements. We probably want the same thing, and it's a question of whether we can spell those things out.

Let me just ask you on your concern about the cost; and that's a concern to us, because if the costs are in the neighborhood of what you suggest here we would be very concerned indeed about it. We want to go into that with you a little bit further.

Mr. NORMAN. All right.

Mr. PREYER. I wish you would give us, in more detail, some specifics on your cost estimate that you give here on the top of page 6.

Mr. NORMAN. We could do it right now.

Mr. PREYER. But if you could give us something to submit for the record on that, a breakdown of your \$1.8 million per year.

Mr. NORMAN. I will.

Mr. PREYER. Now the reason I ask, that seems high from what we have heard from other testimony. Federal hospitals which have had to implement more burdensome records laws have reported very small costs in this area. The cost of the Privacy Act for all U.S. public health hospitals and clinics all over the country, for 1979, was less than \$200,000 for all of them, around the country. If that's wrong and your cost of \$1,877,000 just for the State of Indiana is right, that's a big—somebody is off base there. And if the costs are anywhere in that neighborhood, I don't think you're going to find Congress very eager to proceed or pursue this.

But we are interested in that cost figure. If you could give us more on your figures on that, that's one of the things we are going to be pursuing in our testimony.

Thank you, very much.

Mr. Kindness?

Mr. KINDNESS. I have no questions, but I want to thank you for your testimony here today. It's interesting to differentiate a bit with regard to the long-term health care facilities as compared to hospitals, and I think there is a difference to be taken into account.

While I am not as familiar with the situation in Indiana as in Ohio, having served in the Ohio General Assembly I am somewhat aware of the activity, the legislative activity, that surrounds the long-term health care facilities and in the regulations you run into, as well as some of the things that HEW still has in store for you.

Mr. NORMAN. Right.

Mr. KINDNESS. I thank you, very much.

Mr. EVANS. Thank you, Congressman Kindness.

For the sake of time, I won't ask any questions. But I do want to correspond with you if I may, Mr. Norman, on a couple of points.

Mr. NORMAN. Very good.

Mr. EVANS. And I appreciate your coming here today.

I see Mr. Norman in Washington every few weeks or so, it seems like, and he is quite well educated and is a real expert on medical legislation that comes along in the Congress of the United States. We appreciate your being here.

Mr. NORMAN. Thank you very much. Thank you, gentlemen.

Mr. EVANS. I would like to ask Mr. Gale Coons of the Indiana State Dental Association to come to the witness table, please.

Mr. Coons has worked for the Indiana State Dental Association since 1960 and is currently the executive secretary. Prior to 1960, Mr. Coons was employed by the Indiana State Board of Health in public health service. His credits include a number of articles and filmstrips pertaining to dental health and is a member of the Indiana Public Health Association, Society of State Directors of Health and Physical Education, the Indianapolis District Dental Society and a member of other organizations.

Welcome, Mr. Coons. If you would like to summarize your statement at this time, we would appreciate it.

STATEMENT OF GALE COONS, EXECUTIVE DIRECTOR, INDIANA DENTAL ASSOCIATION, INDIANAPOLIS, IND.

Mr. COONS. Thank you.

Chairman Preyer and members of the committee, I am Gale Coons, executive director of the Indiana Dental Association. I am here representing President Lloyd Phillips, who is president of the dental association.

The association is pleased to have this opportunity to express our points of view with respect to the important subject of privacy of medical records. We understand the word medical in the context being discussed here today refers to dental records as well.

I realize we will be coming near the end of the list of witnesses and will be covering some of the same grounds, so I will keep it mercifully brief.

While H.R. 2979 is limited to those records found in medical facilities and does not affect the offices of individual practitioners, there are some dentists, particularly oral surgeons and a few general practitioners, who provide dental care in hospitals, extended care facilities and nursing homes. For this reason, we have a direct interest; and more indirectly, we are interested as responsible members of the health profession. We recognize how important it is to protect the privacy and confidentiality of medical records. By so doing, it helps to assure free and open information from the patient to the health care provider which is essential, in our opinion, for diagnosis and treatment.

In general, we agree with the intent and basic concepts of H.R. 2979. As Congressman Preyer stated in the introduction of the bill, it is a starting point for discussion. In that regard, we respectfully wish to offer the following points for the committee's consideration.

With regard to the correction of medical records, it is important for all concerned to have correct records. We can understand how at times, under stress, wrong information could be given and recorded; and this should be corrected. However, the committee should understand that oftentimes medical information placed in the patient's record is a matter of professional judgment by the health care provider. There should be sufficient provision in any legislation to protect unnecessary and costly changes with respect to the professional judgment portions of medical records. If this is not done, it could cause the health care provider to be inhibited, in our opinion, in what is recorded and results in less than adequate

diagnosis and treatment. Wording in the order of "with the exception of professional judgments" might be added or at least considered in this section.

All of us are concerned, as it has been said here before, and actively engaged in every way feasibly possible to contain health care costs. Here in Indiana, we are pleased and proud of the voluntary rate review system which has kept hospital costs for Hoosier citizens significantly below national averages and those of surrounding States. Too, I would be remiss if I did not point out that dental fees have not increased as much as other health care costs and have been well below the consumer price index for over a decade.

We believe this is true because of increased production and efficiency, preventive measures, improved methods, techniques and materials, and a sincere, conscientious effort on the part of all practitioners to hold costs down. We respectfully direct the committee's attention to the sections of H.R. 2979 requiring medical facilities to increase their bookkeeping and/or administrative procedures. All of us need to bear in mind that whenever we add on procedures there is a cost factor. Special attention should be given to all such legislative requirements and ask ourselves: Is it really necessary or is it already being done in a satisfactory manner, to safeguard the public's interest as well as the pocketbook?

Finally, we believe the public would be better served if Congress were to encourage and otherwise delegate duties and responsibilities to the States for privacy of medical records. The American Medical Association has drafted model State legislation that provides the needed protection at the State level. We believe the public would be well-served if the committee would give due consideration to and implementation of State level provisions.

Thank you, Congressman Preyer and members of the committee, for receiving the association's statement, in particular, on H.R. 2979 and the importance of maintaining the privacy and confidentiality of sensitive medical records in general.

Mr. EVANS. I have two questions I would like to ask you very briefly, Mr. Coons.

Mr. COONS. Surely.

Mr. EVANS. Do dental guidelines or do the ethical guidelines for the disclosure of dental records vary from those affecting medical records?

Mr. COONS. Not that I know of.

Mr. EVANS. How often—and I presume that they do—do law enforcement personnel ask for access to dental records, in your opinion?

Mr. COONS. Not too often, except in abused child cases, accidents, forensic dentistry, that sort of thing.

Mr. EVANS. Disaster situations?

Mr. COONS. Yes, such as the disaster we had in Chicago not long ago with the airlines.

Mr. EVANS. Chairman Preyer?

Mr. PREYER. I just want to thank you for your testimony. We have been talking about the sensitivity of medical records and the sensitivity of bank records, and I would assume dental records don't have quite the same kind of sensitivity as far as an unauthor-

ized release goes and the effects of it. But from what you have just said, I am a little surprised there are more requests for those records from law enforcement people and disasters like the airline crash—

Mr. COONS. Many times, that's the only way of identification.

Mr. PREYER. I particularly want to congratulate you on the job that the Dental Association has done on keeping fees down in the State, and you also mentioned your hospital costs are down relative to others. That's no mean feat. Indiana ought to be proud of that.

Mr. COONS. We are.

Mr. PREYER. Thank you.

Mr. EVANS. Congressman Kindness?

Mr. KINDNESS. Thank you, Mr. Evans.

I want to thank you, Mr. Coons, and compare notes with you later on your statement about surrounding States' hospital costs.

Mr. COONS. I would be glad to.

Mr. KINDNESS. Thank you.

Mr. COONS. I would just like to briefly comment at this point that I wish the experiences crossed over this Nation were as good as the experiences and the situations that we have here in Indiana. So often, in regard to dental and medical facilities, rates and so forth, often I think some of my colleagues do not believe some of the facts and figures that I share with them on the situation in various areas here in the State of Indiana.

Thank you very much, Mr. Coons.

Mr. COONS. Thank you, Congressman Evans.

Mr. EVANS. Also we have with us here today—I would like to ask to step up to the witness stand if he would; and he has a statement which we have had an opportunity to look at—Dr. Popplewell, who is the president of the Indiana State Medical Association.

Welcome, Dr. Popplewell.

STATEMENT OF DR. ARVINE G. POPPLEWELL, PRESIDENT, INDIANA STATE MEDICAL ASSOCIATION, INDIANAPOLIS, IND.

Dr. POPPLEWELL. Thank you.

Mr. EVANS. We are pleased to have you with the subcommittee this afternoon. And if you would like to summarize your statement, we would appreciate it.

Dr. POPPLEWELL. Thank you.

Many of the comments that are in my statement have already been made, and there is no reason to duplicate them again at this time.

Mr. Chairman, I am Arvine G. Popplewell, M.D., an internist specializing in chest diseases in Indianapolis and president of the Indiana State Medical Association.

Parenthetically, I might mention that for 19 years I was the chief executive officer of the State hospital on this campus in the northeast corner and have first-hand experiences about the problems that this committee has involved itself in.

The State medical association represents about 5,000 physicians in Indiana, and we share the principle of privacy of medical records, whether they be in health care institutions or physicians' offices, and feel very strongly that this must be preserved. Historically, physicians have protected the confidential privileged nature

of any patient communication and I believe recent public opinion surveys support this contention by revealing that the public probably trusts the physician above all others to safeguard the patient's right to privacy of his medical records.

It is our position that the medical notes made by a physician in private practice are for his own use in treating a patient and belong to him. With the patient's consent, the record may be examined by an attorney, another physician engaged by the patient, or other persons that may have legal rights by law to do this.

Those records that the physician makes in the hospital we feel are also his own, but because of the necessity of having organized medical staffs this private, privileged communication has been turned over to the hospital for safekeeping. I won't need to go into the responsibilities, as they have already been mentioned.

As you know, the physician record generates a vast amount of information; much of it is judgmental. In the proposed legislation, there are some exceptions to the kinds of medical information that may be released, specifically having to do with mental illness. I want to mention here that the average physician in his practice deals with mental illness in many of his patients, albeit not the type that has required hospitalization. And many of the notes that he might have even in the hospital record of nonpsychiatric patients would have mental illness overtones.

We have found, through survey, that 14 States as of January 1979 had statutes—and 12 of these have been enacted since 1975—addressing this issue. We personally feel that going through the State mechanism is a more appropriate way of having to take care of the problem of confidentiality of medical records than the Federal way, with the possible exception of those having to do with the beneficiaries of Federal programs. It is quite possible that these might need to have something done on the Federal level.

I would also mention that the house of delegates of the AMA approved a model bill in 1976 for the confidentiality of health care information, for the very purpose of trying to encourage the membership to promote this kind of legislation at the State level.

I would reiterate what some of the other individuals have mentioned with regard to the giving out of information to persons such as Secret Service agents, police officers and so on. It is our view that these people have no more right to the medical information of a patient than anybody else. If this information is necessary, then we feel that we can rely upon our courts to make that determination and give the appropriate subpoena or court order to have this information available.

Therefore, we feel, except as where required by law, the information of a physician about his patient should not be given out except by express agreement of the patient to anybody else—only by a subpoena of the court.

Thank you.

Mr. EVANS. Thank you, Dr. Popplewell.

I have not yet looked at the model bill that the AMA approved back in 1976, although it was a part of the committee print, I believe, that we issued this past year in regards to the medical records privacy legislation. We will be hearing from spokesmen for the AMA in Washington later on, in the committee's consideration

of this matter. But I do appreciate the Indiana State Medical Association's position, at this point, on the early draft of the bill.

We appreciate your being with us here this afternoon.

Dr. POPPLEWELL. Thank you.

Mr. EVANS. Chairman Preyer?

Mr. PREYER. Thank you.

You have given us some excellent food for thought here. It was a very good statement.

I will just mention two things, since we are a little short on time and we could talk about this a long time. But you raised the point about mental illness and about notes which a doctor may make in that connection on a psychiatric patient. That's the most troublesome area, I think, we have run into as far as patient access with that type of doctor's notes. That's something of great concern to your committee, and we are going to look at that very carefully.

Also on your suggestion that State model legislation is the way to go rather than Federal legislation, I just wanted you to know that the committee has a completely open mind about that. Just because we propose legislation doesn't mean that we are trying to persuade ourselves or anybody else that that's the way we ought to go. We want to look at all of the State model legislation. So, that may well be the best way to go, maybe some sort of mixture of State and Federal work on the Federal hospitals, as you indicated.

We appreciate your testimony very much.

Mr. EVANS. Congressman Kindness?

Mr. KINDNESS. I will just add my thanks. The considerations of whether State or Federal action is necessary are sometimes thought, by some people, as being sort of a delegation from the Federal Government to the States. I tend to look at it the other way around. The States were here first.

Mr. EVANS. Thank you, Congressman Kindness.

Dr. POPPLEWELL. Thank you, very much.

Mr. EVANS. Thank you.

I would like to finally then ask Harwood Prince, who is the director of the medical records for the I.U. hospitals here in Indianapolis, Ind., to please step forward. If you could share with us a condensed version of your statement which we have, we would appreciate it.

STATEMENT OF HARWOOD PRINCE, DIRECTOR OF MEDICAL RECORDS, INDIANA UNIVERSITY HOSPITALS, INDIANAPOLIS, IND.

Mr. PRINCE. Thank you.

Mr. Chairman, I am Harwood Prince, a registered record administrator, director of medical records for the Indiana University hospitals, Indianapolis, Ind. It is indeed a pleasure for me to address the subcommittee today. The Indiana University hospitals are the major tertiary referral hospitals serving all 92 counties of the State of Indiana.

The privacy of medical records and medical information is an increasingly critical item in our industry, and we congratulate your subcommittee on the initiative it is taking in addressing some of the issues related to this topic. Our hospital is very supportive of the principle of confidentiality and the necessity to recognize and

involve, where appropriate, the patient or his legal guardian in the management of that information. Our hospitals have a nine-page policy and procedures statement, entitled "Confidentiality of Patient Health Information," which deals directly with this topic. And if you will permit me, I would like to just read the brief introductory paragraph which is our basic policy on this topic.

The medical record is the property of the Indiana University hospitals and is maintained for the benefit of the patient, the medical staff and the hospital. Its primary purposes are to serve as a basis for planning and continuity of patient care, to furnish documentary evidence of the patient's care, to document communication between the practitioner and other health care professionals contributing to the patient's care, to assist in protecting the legal interests of the patient, the hospital and the practitioner, and to provide data for use in continuing education and in research. All information in the record should be regarded as confidential and available only to authorized persons. The patient or his authorized representative is entitled to information in the medical record of the patient through a procedure approved by the attending physician, unless the physician certifies that the release of such information to the patient would be detrimental to the patient.

You will note, therefore, that the current practices at Indiana University hospitals make provision for the patient to have access to the information in his medical record. And while this procedure has only been used a very few times by patients, when it has been used it seems to have been satisfactory to all parties concerned.

We believe that this policy statement of our hospitals is consistent with the intent of your bill; therefore, as this bill affects our hospitals, the following comments will be related to the consequences upon us if the bills are enacted in their current form.

First, in at least nine sections of the bill that we could identify, it calls for the Secretary of HEW to establish guidelines and procedures that would affect and dictate the protocols and guidelines that we in our hospitals would need to follow to comply with the intent of your bill. The track record of the Department of HEW to develop acceptable procedures and guidelines that the hospitals have to follow is questionable, because of the costly extensive bureaucracy included with such regulations. Such regulations, in fact, may divert from the intent of the original bill; and therefore, we feel it is essential that your intentions are defined as much as possible to minimize the risk of distortion when regulations are written.

Second, a considerable administrative burden which would affect us relates to the issue of correction of medical records as spoke to in section 112 of the bill. The provision requires that if a patient in the hospital should amend any content of the medical record, the hospital would be required to inform all persons of the amendment who may have received a copy of the record previous to the time of the amendment. This is a burden almost beyond calculation.

We would strongly recommend that this section be excluded. If it should be included, there should be some expression of the statute of limitations on the right of the patient to make amendments to their medical records or it should be indicated that the hospitals have the right to establish this policy for themselves.

Third, we feel that section 111, paragraph C, is inappropriate. This calls for the Secretary of HEW to publish recommendations and recommended criteria by which medical care facilities would determine whether the inspection by an individual of that person's

medical record might reasonably be expected to cause sufficient harm to that individual so as to outweigh the desirability of permitting the inspection. We consider this an extremely dangerous provision of this bill, because it essentially means that HEW will be establishing the guidelines for what information could harm or could not harm a patient. We believe that this is a physician judgmental issue and not one that can be established by the Government. Therefore, we would strongly recommend this paragraph be excluded from the bill.

I would be remiss if I did not address the potential cost to our hospitals and the health care system in implementing a new set of bureaucratic regulations. Our hospitals admit approximately 20,000 patients per year and have approximately 175,000 outpatient visits per year. If we are to assume that 1 percent of the patients who received care in our hospitals desire to exercise their rights in reviewing their medical records as provided under this bill, we estimate we could receive 8 to 10 requests per week. Based on our experience with patients or their legal representatives who have had inquiries in the past and the amount of coordination required with all entities involved, we estimated that we would experience additional cost in the area of \$35,000 to \$45,000 per year for just new personnel required, to say nothing of the other personnel in other departmental areas who would have to be called upon to assist in the areas of interpretation, consultation, et cetera, in answering the questions that may be raised.

The impact of cost not only would serve to increase the cost of operating federally mandated programs, such as medicare and medicaid, but also is felt by other insurance carriers and the patient himself. As not all patients are covered by insurance programs, the hospital, too, must bear the burden from increased cost of regulations and spend precious dollars that could much better be spent in providing direct care to our patients.

We would request that any bill on medical record privacy exclude this possibility from happening.

In closing, I would again like to thank you for the opportunity to comment. Perhaps it is a bit naive on my part to make the following suggestion, but because we are in basic support of the intent of your bill and most of the basic principles addressed throughout, but are not supportive of the administrative consequences of the bill, we wonder if your objectives could be achieved by restricting the content of your bill to your two basic objectives and not include any provisions for the Department of Health, Education, and Welfare to prepare administrative regulations. Simply said, this would mean that hospitals who wish to participate in medicare and medicaid would be obligated to institute policies and procedures that are consistent with the objectives that you have appropriately indicated. Annually, through current medicare and medicaid survey processes of hospitals, these surveyors could verify compliance with such a policy. Hospitals would then be obligated to comply with your objectives, and the hospital industry could benefit by allowing itself to apply its own talents to addressing how to comply with these issues and avoid the unpredictable and costly form of regulations being imposed upon you by the Federal bureaucracy.

Thank you again, Mr. Chairman.

Mr. EVANS. Thank you.

I appreciate your comments there, and I think certainly the subcommittee would agree with the objectives that you mentioned there in the closing paragraph. And we have heard from the American Medical Records Association witnesses in Washington, a few months ago I believe it was, as you may be aware, and they were basically supportive of the approach the bill took; but, at the same time, we need to make sure that whatever regulations and cost burden that might potentially result from this bill be kept to an absolute minimum. And to that end, I know the subcommittee will be doing its best.

Congressman Preyer?

Mr. PREYER. I want to thank you, too, for some excellent suggestions and commend you on your current practices at the Indiana University Hospitals as you have outlined it here. If all of the hospitals operated the way you did, we wouldn't be talking about this kind of legislation. In fact, I think it tends to be true of Indiana and, I have to say, North Carolina too. But the laws come about because not everybody is functioning as effectively as you are in your hospitals.

We certainly understand your feelings about overregulation, and I will be glad to confer your warm regards to Mr. Califano. We appreciate your comments.

Mr. EVANS. Congressman Kindness?

Mr. KINDNESS. Thank you, Mr. Evans.

I don't know how I could top that. I just thank you very much.

Mr. EVANS. Thank you very much, Mr. Prince.

I understand Dr. Donald Moore, who's a medical director at Larue Carter Memorial Hospital here at the I.U. School of Medicine, is with us this afternoon, although I don't believe you have a prepared statement. Is that correct?

STATEMENT OF DR. DONALD MOORE, DIRECTOR, LARUE CARTER PSYCHIATRIC HOSPITAL, INDIANAPOLIS, IND.

Dr. MOORE. I don't have copies.

Mr. EVANS. I see. Could I possibly ask you if you would make copies, about a half a dozen, available to my office? I will make sure that other copies are made and distributed to all the subcommittee members.

Dr. MOORE. While your members are here, sir, I have one page that I think they would like to hear, because of the problems in mental illness, and leave the rest.

Mr. EVANS. All right, fine.

Dr. MOORE. I am Dr. Donald Moore, professor of psychiatry and medical director, of the Larue Carter Psychiatric Hospital here. I have been here for 24 years. And many of the questions you have raised today, I had some additional answers for. But I won't take time for that, because I know you are short of time.

I had three points to make, but one of them was that medical records in the psychiatric hospital are somewhat different; and they constitute a unique problem. Psychiatry has been probably labeled erroneously, I believe, as an inaccurate or nonscientific branch of medicine. It's true there are many things we don't know. We don't have the answer, but there's a vast volume of popular

clinical and research data which, in many types of psychiatric problems, provides accurate and correct data as to the management of the case.

But from a legal point of view, psychiatry may be one of the least accepted of the medical specialties. Primarily because the psychiatrist and frequently other members of his treatment team (a) do not limit their data gathering to only positive direct testimony of the patient, but obtains "hearsay" evidence from other members of the family; and (b) may not have specific laboratory tests that absolutely confirm a specific psychiatric diagnosis. In fact, the majority of patients, at different periods in their life history, may give data suggesting two or more major reactions or diagnoses. And what was the best impression or diagnosis based on data available 10 years ago may not be the same best impression based on current history and present symptoms. People change. Patients change.

Furthermore, particularly in psychiatry and especially if the patient is clearly psychotic, the physician is unable to rely on only the patient's direct testimony and he is also required to rely on other sources of information, such as the spouse, children, parents, employers and friends. In other words, in the patient's best interests, we are forced in such cases to accept "hearsay" evidence. And we would be negligent if we did not do so.

Now if the total medical record is subject to repeated review and correction—and that's the one thing that I was addressing in my other points, also, the business of the patients having the medical records and reviewing them. By providing a copy of the record to the patient, there are several serious consequences. We would be violating the confidentiality from the other information sources, from the sources other than from the patient. As a result, we would find ourselves, I think—and this is the permutation that we have to postulate—in the physician of not being able to obtain valuable data because third parties fear of being quoted.

Two, subsequently even with relevant hearsay data, there would be reluctance to use such data.

Three, medical records will become increasing sterile and incomplete; and there will be less recording of the possible diagnostic possibilities or possible causes for fear that the hearsay evidence or hypotheses will be challenged in court.

Furthermore, and this is back to the cost item, I think, there are very serious, almost insurmountable operational complications to making a copy of the medical record, particularly a psychiatric record, which would provide data only about the patient available to the patient. Most comprehensive psychiatric records include nurses' notes, progress notes, treatment reviews—they are required by the Joint Commission—and relate in some detail the patient's behavior and progress in terms of activities and socialization with other named patients. There is no practical process that I know of, short of keeping no records, by which such reports should or can be edited to take out the portions which relate to other patients. Thus, the right of patient A to have a copy of his record violates the rights of patient B for confidentiality. This is particularly true if both patients, A and B, are in group therapy.

I am going to quit there. I will send you the rest, just submit the rest of the document, because I think there's some other data you might like.

Mr. EVANS. OK.

Dr. MOORE. But there is a real problem. I am conscious of the time.

Let me lastly call to your attention a small but persistent group of active paranoid patients who maintain they have been harmed or maligned by everyone with whom they have had any relationship: spouse, parent, employers, physicians, lawyers, and I suspect even Congressmen occasionally. These people devote their lives to blaming their own inadequacies on others. To provide them a copy of their hospital record leads to endless litigation.

On a few occasions in the recent past, I have had a request from a lawyer for a copy of such a record. I have asked him if he understood paranoid patients. And, quoting the *Tarasoff* decision regarding the psychiatrist's obligation to warn threatened people, I have informed him that the patient he was inquiring about has successfully incorporated nearly every professional person, doctor, lawyer, ministers, in her paranoid system in the past. If he wanted to take that risk, he was welcome to have the patient's record.

But I suggested he review the patient's complaint pattern and projective accusations with a psychiatrist of his choice before getting involved. Usually he says he will call me back, and usually he doesn't.

Mr. PREYER. I certainly want to thank you for that statement, and you have pointed out truly horrendous problems involved in any kind of disclosure in psychiatric records. We do hope you will send us that for the record.

Dr. MOORE. I will, certainly.

It may lie somewhat in redefining what the medical record is. That's one possible element.

Mr. EVANS. Thank you.

Dr. MOORE. Thank you.

Mr. PREYER. I did just want to say thank you to the Indiana University Medical School once again, for this fine facility they have let us use, and for your staff and the staff at the hospital, for all of the work they have done in setting this up.

It has been a very interesting afternoon for us on the committee.

Mr. EVANS. Thank you, Mr. Chairman.

I very much appreciate Congressman Kindness driving over here and taking time out of his very busy weekend schedule to be at this subcommittee meeting. It's indeed appreciated.

And thank you, Dr. Moore. Even though your statement did come at the end, it shall not be the least. We will be interested in reading your complete statement. It was presented in a most pleasurable manner.

Dr. MOORE. You don't need to carry my message to Califano, but I do wish that my ideas have a prayer for your kindness.

[Dr. Moore's prepared statement follows:]

DRAFT #5
November 13, 1979
Donald F. Moore, M.D.
Larue D. Carter Hospital
Indianapolis, IN

STATEMENT TO BE SUBMITTED TO
GOVERNMENT INFORMATION AND INDIVIDUAL RIGHTS HOUSE SUBCOMMITTEE
REGARDING MEDICAL RECORDS PRIVACY
Saturday, July 14, 1979, 1:30 P.M.

MR. CHAIRMAN, MEMBERS OF THE COMMITTEE:

Thank you for the invitation to participate. I am honored to do so in an effort to focus your attention on the undesirability of including in any legislation which includes any unqualified statement that the patient "has a right to a copy of his medical (hospital) record, particularly a psychiatric hospital record, and the opportunity to correct it." This particular wording and constellation of ideas has appeared recently in many publications focusing on patient's rights both in policy statements, hastily passed state laws, and some judicial decisions.

As a psychiatrist with over 40 years of experience, the last twenty-five as Medical Director of a teaching-research psychiatric hospital on the Indiana University Medical Center Campus, I am the final guardian of confidentiality of over 11,000 patient's psychiatric hospital records. Daily we get at least a half-dozen requests for these records. Most of them are valid and legitimate and require only brief portions of the record which are released only with the patient's signature and after consultation either with the treating physician himself, or, if that person is not available, the Chief of the Service to which the patient was assigned.

The primary consideration always is that such a report is in the best interest of the patient. However, almost weekly there are at least two or three of these requests which are referred from my staff to my attention because in some manner such a released document might not be in the patient's best interest, or there is

a potential violation of confidentiality which requires further discussion and adjudication. I would say that over 90% of these requests, after consultation with the patient or his attorney, can be and are satisfactorily answered, without disclosure of the full hospital record which is neither wanted nor needed.

I appreciate the opportunity to speak on this point and would like to cover it in three ways.

My first comments are to emphasize that my position does not in any way imply any curtailment of the patient's right to access or to be informed regarding his hospital record, but is concerned with any rule, policy or law which implies or requires that the hospital medical-psychiatric record be given to the patient or his lawyer for correction. Second, a brief exposition as to why such disclosures of psychiatric records have specific, dangerous and perhaps illegal complications. One of the most harmful consequences of such disclosures may lead to erosion and destruction of the doctor-patient relationship, particularly in psychiatry. And third, three examples of the type of complication that such legislation can and does foster.

First, in regard to the patient's right to access to his record. I am in complete agreement with the principle and policy that the patient has the right to access to the information in his hospital record. He has the right to know what has been written as well as to know the general outlines of his treatment plan, the potential treatment goals, complications, costs, risks, and the reasons for the physician's medical-management decisions. This mutual exchange of information is the life-blood of the professional relationship between a patient and his treating physician. It is the essential process by which a "therapeutic alliance" between

the physician and a patient is established. It must be done in every effective treatment relationship. The patient's questions must be answered by his or her physician as a part of the patient's therapy. Any satisfactory review of the medical records must be done by the patient's physician or occasionally by another physician acting for the patient or for the hospital. It is only by such an "informed" review and explanation that the physician's treatment decisions can be mutually understood and effectively followed.

NOTE: The above applies primarily to the situation in which the patient is still actually in the hospital as a patient, whether he is a medical, surgical, psychiatric, neurological or any other type of patient. It is in this area that I am in complete agreement both with the American Medical Association, the American Psychiatric Association, and our Indiana State Medical Association in terms of the opinion expressed by Dr. Popplewell that at this state of the relationship it is highly undesirable for the patient to begin with a demand for a copy of his record. It is the responsibility of the treating physician to maintain this personal relationship and to meet the needs of the patient. The intervention of the medical record or third parties or lawyers in most cases indicates a definite disruption of the therapeutic alliance. When this occurs in either the physician's or the patient's opinion, such a review should then be done by another physician of the patient's choice. This follows the principle of the patient's right to a second opinion.

I would add parenthetically at this point that as a physician I have been hospitalized and been a patient in a hospital as has my wife on several occasions. And as long as I have confidence in my physician, I usually prefer to ask him: "What the hospital record says?", "What the laboratory reports are." I value his judgment as a specialist in the illness for which I am being treated rather than looking at the raw data for myself and trying to interpret it. It is only in this way that I

can tell him my worries, express my anxieties, or voice my questions. And thus learn from him or her the explanation or rationale of my treatment process.

There is, however, a second type of request for the record; namely, that coming from a patient who has been discharged from the hospital and is no longer under treatment. Usually he requests that his previous hospitalization record be sent to his current doctor. We assume that at least here in Indiana, as well as in other states, such a report is still medically confidential and is to be used only for the patient's benefit. So this is, with the patient's written authorization, routinely done.

However, there is a third type of request which comes from a relative, or a lawyer, or someone not necessarily operating under the same aegis of confidentiality nor necessarily in the patient's interest. In such cases, we usually make an attempt to have this data go through a qualified physician of the patient's choice. This assures an informed interpretation of the data to the patient, the authorized relative, or the authorized attorney. On the other hand, if the medical examination, the medical decisions, and the medical treatment are not reviewed by a peer, i.e., if anyone other than a physician familiar with the medical terminology and the usual indications or contra-indications to current treatment modalities is not available, such a review of the pertinent parts of the record, cannot be an informed knowledgeable review. Similarly, many lawyers unfamiliar with medical or psychiatric terminology, diagnostic procedures and treatment alternatives, recognize they cannot function as an adequate patient representative nor understand the medical treatment decisions and they choose to utilize a knowledgeable physician for consultation.

My final point on this focal area is that until such an "informed" exchange of information has occurred, questions answered and lack of understanding or misunderstanding eliminated, neither the patient nor his representative is actually familiar

with what is in the record. And what is usually considered a release document by the patient is not based on "informed consent." Without this "informed consent" the patient may not be familiar with the fact that some of the information in the document he is releasing may be harmful rather than useful to him or to the case in point.

Second, the specific unique characteristics of the psychiatric medical record which emphasize the importance of confidentiality. Here, I would comment first from a legal point of view, psychiatry may be one of the least acceptable of the medical specialities. Primarily because the psychiatrist and frequently other members of his treatment team do not limit their data gathering to only positive direct testimony from the patient, but obtains "hearsay" evidence from other members of the family.

Furthermore, particularly in psychiatry, and especially if the patient is clearly psychotic, the physician is unable to rely on only the patient's direct testimony, and he is required to rely on other sources of information such as spouses, children, parents, employers, friends. In other words, in the patient's best interests, we are forced, in such cases, to accept "hearsay" evidence. And we would be negligent if we did not do so.

Second, a psychiatrist does not have specific laboratory tests to absolutely confirm many psychiatric diagnosis. In fact, a majority of patients at different periods in their life may give data suggesting two or more major reactions or diagnosis. What was a best impression based on data available ten years ago may not be the same best impression based on current history and present symptoms. Patients do change.

A third special problem related to providing copies of a whole psychiatric hospital record to a patient or other third parties. This is particularly serious if the total medical record is subject to routine review and correction rights. To provide a copy of the complete record to the patient would violate the confidential information from sources other than the patient. Most psychiatric hospital records contain considerable data from such other sources. As a result we would find ourselves in the position of not being able to obtain valuable data because (1) The third parties fear of being quoted. (2) There will be a reluctance to use such "hearsay" data. (3) Medical records will become increasingly sterile and incomplete. (4) There will be less recording of possible diagnostic possibilities, or possible causes for fear the "hearsay" evidence or hypotheses will be challenged in court.

Fourth, there are very serious, almost insurmountable operational complications to making a copy of a medical record available to a patient, particularly a psychiatric record which would provide data only about the patient. Most comprehensive psychiatric hospital records require nurses notes, progress notes, treatment reviews relating in some detail, the patient's behavior and progress in terms of activities and socialization with other named patients. There is no practical process that I know, by which such reports should or can be edited. To take out the portions which relate to other patients is a logistic nightmare. Thus, the right of patient A to have a copy of his record violates the rights of patient B for confidentiality. This is particularly true if both patients, A and B, are in group therapy.

A few examples to illustrate:

As an intern in 1939, I had a very sick patient with a partial obstruction of the bowel due to cancer. He was on intravenous feedings and a suction tube yet he repeatedly vomited black material which looked like food or congealed blood. Yet

he was getting no food and he had no other evidence of hemorrhage. The nurses and attendants denied feeding him anything as did his family and visitors. But his stomach tube was plugging up two or three times a day - requiring many hours of unplugging and removal, cleaning and reinsertion of the tube - which was traumatic to both patient and physician. Neither the nurses, the staff doctor, nor I were able to figure out the answer.

Finally, one day when the patient was sleeping, a neighboring patient called me over and quietly told me he thought he had the answer which he would tell me if I would not let the patient know that he had informed me. I assured him of confidentiality. He then informed me that the patient's relatives brought him five or six cigars every day. He was always out of them and welcomed them, but the neighboring patient had never seen my patient light up a single cigar. He concluded, correctly, that the man was chewing and swallowing his cigars. If my patient had at that time had the "right to a copy of the chart" he would have made a liar out of me for promising confidentiality to his neighbor.

A second example. Dr. Alice Pickett, Professor of Obstetrics and Gynecology at the University of Louisville, one of the first full-time women professors in a Medical School in this country, after her retirement, volunteered to work for the Red Cross in a Bloodmobile during World War II. At the age of 80, she was doing the brief histories and physicals required of blood donors. She briefly noted as part of the record, "Not acceptable. S.O.B."

When a hustky mountaineer was told he could not be used for a donor, he grabbed the slip, dashed back to Dr. Pickett and knocked her down, accidentally breaking her wrist. He loudly exclaimed, "No one, doctor or lady, can call me a S.O.B."

When it was explained to him that S.O.B. was the medical abbreviation for shortness of breath and Dr. Pickett was only protecting him from more serious complications, he explained that he was an orphan who never knew his mother and he had a lifelong history of knocking down anyone who said S.O.B. to him. He apologized, but Dr. Pickett's wrist was still broken.

Last, I would call to your attention a small but persistent group of active paranoid patients who maintain that they have been harmed or maligned by everyone with whom they have had any relationship - spouses, parents, employers, physicians, lawyers - and I suspect even Congressmen hear from them occasionally. These people devote their life to blaming their own inadequacies on others. To provide them a copy of their hospital records leads to endless litigation. On a few occasions, in the recent past, when I have received a request from a lawyer for a copy of such a record, I have asked him if he understood paranoid patients. And quoting the Miranda Decision in California regarding a psychiatrist's obligation to warn threatened people, I have informed him that the patient he was inquiring about had successfully incorporated nearly every professional person - doctors, lawyers, ministers - in her paranoid system in the past. If he wanted to take that risk he was welcome to do so, but I suggested that he review the patient's complaint pattern and projective accusations with a psychiatrist of his choice before getting involved. Usually he says he will call me back. Usually he doesn't.

IN SUMMARY, it is my medical psychiatric opinion that:

1. The hospital record should remain the property of the hospital.
2. Patients should have access to the information, preferably from his or her hospital physician, or their own family physician, or if appropriate through an informed lawyer.

3. The major purpose of the confidentiality of the record must always be the protection of the patient.
4. Before releasing the record to other parties, the patient needs to know, in general, what is in the record; otherwise, there is not "informed" consent.
5. Relevant material, in the patient's interest, must be available to the patient, other physicians, lawyers and the Courts.
6. Relevant material, in the public's interest, must be made available to the Courts.
7. But free access to copies of the record for "fishing expeditions" without preliminary discussions:
 - (a) may not be in the patient's best interest.
 - (b) may violate the confidentiality of other sources of information.
 - (c) may violate the confidentiality of other patients.
 - (d) may set up an implied task of editing which would be nearly impossible.
 - (e) may lead to interminable litigation at high cost to the State.
 - (f) is not in the best interest of the patient, his relatives, other patients, the hospital nor the public.

When I'm a patient, I don't ask to see my record. I talk over problems with my doctor.

Thank you for the opportunity to express myself on this important subject.

May I hope that the ideas expressed have a preyer for your kindness.

Mr. EVANS. I recognize Chairman Preyer to adjourn the meeting.

Mr. PREYER. The subcommittee stands adjourned, with appreciation to the good citizens of Indiana.

[Whereupon, at 5 p.m., the subcommittee adjourned, to reconvene subject to the call of the Chair.]

PRIVACY OF MEDICAL RECORDS

MONDAY, SEPTEMBER 17, 1979

HOUSE OF REPRESENTATIVES,
GOVERNMENT INFORMATION
AND INDIVIDUAL RIGHTS SUBCOMMITTEE
OF THE COMMITTEE ON GOVERNMENT OPERATIONS,
Washington, D.C.

The subcommittee met, pursuant to notice, at 10:10 a.m., in room 2247, Rayburn House Office Building, Hon. Richardson Preyer (chairman of the subcommittee) presiding.

Present: Representatives Richardson Preyer, Glenn English, and Thomas N. Kindness.

Also present: Timothy Ingram, staff director; Robert M. Gellman, associate counsel; Euphon Metzger, secretary; and Thomas Morr, minority professional staff, Committee on Government Operations.

Mr. PREYER. The committee will come to order.

Our first witness today is Dr. Sidney Wolfe. We are glad to have you here, Dr. Wolfe, from the Health Research Group.

Dr. Wolfe was scheduled to testify at an earlier hearing and we were not able to make connections. We have been anxious to discuss medical records privacy with Dr. Wolfe. So we asked him to be here today.

Dr. Wolfe, you may proceed in any way you wish.

STATEMENT OF DR. SIDNEY M. WOLFE, PUBLIC CITIZEN HEALTH RESEARCH GROUP

Dr. WOLFE. As I will discuss in greater detail, we are very much in support of the idea of using the leverage that is available under medicare and medicaid to improve the quality of health care.

We have seen other examples of this recently. It is interesting how long it has taken, considering how long medicaid and medicare have been in place.

I am reminded of the regulations last year under medicaid that say, "No longer can Federal funds be used to pay for hysterectomies which are done for the purposes of sterilization, a surgical procedure which, in the context of sterilization, is really unduly expensive and dangerous."

In putting this regulation out, HEW is essentially saying that since we are paying the bills for medicaid recipients, we would like at least for them to have better health care by disallowing payment for this particular procedure which we don't believe is in their interest.

Unfortunately, the leverage is not there to extend the same policy to nonmedicaid recipients. But I suspect that the initiative

taken by HEW on that issue will lead to a rapid decline in those hysterectomies that are not funded out of medicaid.

Here, too, in the case of access to medical records, the initiative in this legislation to give access under medicare and medicaid to those people who are getting care in medicare and medicaid facilities is again going to spread to other areas of the health care system.

It is long overdue that people are not getting a record, if they so choose, of this most expensive kind of interaction that they are engaged in. The fact that the medicare-medicad recipients themselves aren't paying as much money out of pocket as other recipients doesn't make much difference, in general.

So we are delighted to see those moves begin and support with some exceptions what your subcommittee is doing.

In August of 1978 we published a booklet which we have submitted for the record called "Getting Yours: A Consumer's Guide to Obtaining Your Medical Record," which contains a discussion of what is in a patient's medical record, why access to it is important, a State-by-State description of medical record access laws, and a step-by-step guide for patients to getting and using their own medical records.

This is most easily accomplished if they live in a State where there is access. This project was prompted, as in the case of many of our projects, by a very large number of complaints from people who wanted to know what had been done to them. Short of becoming engaged in malpractice litigation where their attorneys could, get a copy of the record, these people were not quite at that point and wanted to see what had gone on with them.

If they happened to live in States where there were not access laws, they could not get them. In many instances, however, people who do, in fact, live in States where there were access laws wrote to us and were not aware that there was an access law.

To try to shorten our work and inform people in a more standardized way, we wrote this book and published it.

In most States, as we have said, it is easier to get your CIA or FBI files than to obtain your medical records. Doctors and hospitals can refuse access altogether with impunity or tell the patient only what they want him or her to know.

Freer patient access to patients' own medical records could have a profound impact on the health care system. Medical record expert Dr. Lawrence Weed of the University of Vermont states that access to medical records "may be the most effective weapon we have against overutilization of medical care, with its dangers to society—mentally, physically and economically."

The transmission of information from physicians to patients about medical conditions and treatment will improve therapy through better communication, understanding and compliance with treatment plans.

In the booklet, "Getting Yours," we review some examples of studies where patients have been given their records and discuss sorts of improvements which have occurred. Patients can avoid expenses and medical risks by relying less on their physicians and more on their own participation in preventing and treating illness and injuries.

Drs. Vickery and Fries in their book "Take Care of Yourself" have estimated that 70 percent of all outpatient visits to physicians are unnecessary.

Finally, patients cannot safeguard their privacy rights unless they know the contents of their medical records and consent to their release to third parties only when they think it appropriate or when a genuine and substantial public interest demands it.

Doctors and hospitals opposed to free patient access say that patients won't understand the records, that record keeping will suffer, and that too much information might be harmful to patients.

In fact, they may really be saying that they won't take the time to talk to their patients, that they might be embarrassed by the poor quality of their records—or their treatment—and that they want to keep patients ignorant and dependent on them.

The same kind of logic has been put forth by a number of professional medical groups and the drug industry in attempting to stop the FDA from providing women with patient package information about the use of estrogens in the menopause.

It was stated that this kind of information would interfere with the doctor-patient relationship which in a sense it would if the doctor had not bothered informing the woman about the benefits and risks of these drugs.

In the same way, trying to increase the flow of information to a patient about his diagnosis and treatment should improve the doctor-patient relationship rather than worsen it in the sense that a better informed patient can comply with the treatment if it makes sense and is in a better position to ask questions about what is going on.

I will now just go into several suggestions listed on pages 3 and following in the written testimony about ways that we believe this legislation could be improved.

We see no justification for confining the right to patient access to institutional medical records, and excluding records maintained by private physicians. Such a restriction would prevent patients from gaining access to records concerning by far the most frequent type of medical treatment—the physician-patient encounter in a private office.

In 1976, the ratio of noninstitutional physician visits to hospital admissions was more than 28 to 1. Similarly, there were approximately 10 times as many noninstitutional physician-patient encounters as hospital outpatient visits, which includes both emergency room and ambulatory clinic visits.

In addition, we have found that hospitals are more likely than physicians to afford patients access to their own records in States where access is not required by law.

Consequently, by excluding private physicians, the bill ignores the overwhelming majority of medical records to which patients have been denied access. We recommend that permitting a patient access to his own medical records and a right to make corrections be made a condition of physician as well as institutional participation in medicare and medicaid.

We also strenuously object to section 111(b), which allows medical facilities to deny patient inspection if they determine that

"inspection might reasonably be expected to cause sufficient harm to the individual so as to outweigh the desirability of permitting access."

In the virtually unfettered and vaguely stated discretion it grants providers to refuse patient inspection, this provision creates an exception which potentially swallows up the general rule stated in section 111(a)(1) that, "A medical care facility shall permit an individual to inspect any medical record that the facility maintains about the individual."

In its extensive public hearings on access to medical records, the Privacy Protection Study Commission found that, "Not one witness was able to identify an instance where access to records has had an untoward effect on patient's medical condition." As noted above, studies have shown just the opposite effect.

Even if the bill could identify and describe more specific circumstances under which patient access might be inappropriate, creating an exception to access would not be desirable. Patients denied access for such reasons would be likely to engage in anxiety-producing and therapeutically counterproductive speculation about the reasons underlying nondisclosure.

If the patient successfully inferred from a limited list of statutory exceptions the provider's basis for nondisclosure, the intent behind denying inspection would have been seriously frustrated.

On the other hand, a set of specifically enumerated criteria for nondisclosure might prompt erroneous patient speculation which would be equally inimical to a healthy and productive physician-patient relationship.

Thus, we are convinced that specifically stating such criteria would be an unsatisfactory response to the problems of overbroad discretion and we reject any paternalistic attempt to protect the patient from his own medical records. Section 111(b) should simply be removed from the bill.

If the subcommittee nevertheless decides to deny direct patient access at the provider's discretion, the appropriate person designated by the patient to inspect the records on the patient's behalf should be broadly defined—that is, the patient should be allowed to choose whomever he or she wishes and to communicate freely with that person about the content of the medical record.

This position is similar to that of the Privacy Protection Study Commission which said,

In no case, however, should the physician or other keeper of the record be able to refuse to disclose the record to the designated responsible person, even when it is known in advance that the designated person will give the patient full access to it.

The implication of placing barriers in the way of those seeking their medical records has been well stated by Ed Mulligan of Syracuse, New York, a leader in the battle to obtain unrestricted access to medical records, a battle which started with his own fight to get his record and which extended to others in the State of New York.

Mulligan has said,

A society that denies a person knowledge of his own state of health is toying with tyranny and is able to maintain this censorship only because in general the victims are weak, sick, alone and helpless.

Federal legislation or State legislation on access and confidentiality? It makes no more sense to have different medical record access rules in one State than another, seen most ridiculously in places like the District of Columbia area where you have three State jurisdictions than it does to have the States be allowed to decide whether or not medicaid funds should be used or not used to pay for a sterilization, hysterectomy.

Whereas there are a number of circumstances where States rights can and should be upheld, I don't believe this is one. The human body does not differ from State to State.

Hopefully, there are not the extraordinary swings in quality of medical care that exist from State to State such as exist in any given State. I don't think it makes any sense to allow the States to decide as they have thus far whether they want to give the States right to access to their record even though the Federal Government is paying the bill in the bulk of these circumstances.

It reminds one of the situation with occupational safety and health protections for workers that existed up until the time there was a Federal OSHA. One State could have a very strong policy with respect to protecting a worker from workplace hazards and the same worker, were he to move to another State and be faced with the same set of occupational hazards, would not be protected.

I don't think those kinds of States' right determinations make any sense.

We also have commented on public disclosure of patient records. We believe that section 123 should be changed in ways which are discussed in detail.

Access for researchers, section 124, we strongly support the idea that epidemiological investigators are the main people needing access to these kinds of records and they should gain access to the records without specific patient consent.

The record that they have put forth for doing this without disclosing personally identifiable information is excellent. I am not aware of any breaches in it. Many of the most important advances in the knowledge of occupational risks, the risks encountered by patients upon using certain drugs, et cetera, have come from such studies.

We would hate to see them impaired by putting blockades in the way as has been suggested by certain Members of Congress in the past several years.

Lastly, disclosure for fraud and abuses. We believe that section 129(a)(1)(A) which provides for disclosure of patient records to Government authorities for use in an investigation or prosecution of fraud, abuse, or waste should be amended to require the deletion of all patient identifiers.

We can conceive of no circumstances in which the identity of individual patients is crucial to the investigation and prosecution of fraudulent or wasteful federally funded medical care practices. We urge that identifiers be removed from such records in a fashion similar to that called for in section 125(b)(2), a provision relating to disclosure of medical records for audit or evaluation purposes.

Thank you and we would be happy to answer any questions.

Mr. PREYER. Thank you very much, Dr. Wolfe, for your testimony.

On your point concerning the uniformity of legislation and the need for Federal preemption, do you suggest that the Federal laws should simply supersede present State laws or are there some State laws that we should preserve?

Dr. WOLFE. I would answer the question two different ways.

If the amendment, if what you propose goes forth as it is presently constituted; namely, only providing for mandatory disclosure of institutional records, then we would support a preemption proposal that allowed those States with stronger provisions to retain their provisions.

For example, those States that do presently grant not only institutional medical record access but private doctor medical record access. Virginia is an example.

If, on the other hand, the provision is amended as we suggest to include access to records of all outpatient medical records at least then that would be grounds for preemption.

But the State laws are not specific for medicare and medicaid recipient institution to the extent to all care that is going on. I am not aware of any State that has a regulation presently that is confined just to medicare and medicaid recipients.

Mr. PREYER. In the area of medical research, you are sympathetic to the necessity for medical researchers to use medical records. Would you allow them to use those records without patient consent?

Dr. WOLFE. For the sake of conducting epidemiological research; this means that the second they have collected the critical data from the record, that from that point on the patient identifiers are deleted and any subsequent investigation, evaluation of this information, will be done without access to these identifiers.

I would submit for the record a statement that we made on March 30 of this year concerning access to employee exposure and medical records in the context of a regulation put forth by the Occupational Safety and Health Administration of the Labor Department.

Their regulations would allow, in certain circumstances, certain people to have access to these records for the sake of conducting epidemiological investigations.

We believe that their proposal was not strong enough and made a number of suggestions which we would submit to the record here because the same kinds of suggestions, I think, can be made in the context of the other kinds of epidemiological research as discussed in section 124.

But I think that the important thing is that these investigators really can support their contention that there has not been any abuse in terms of disclosing personal identification. They are not interested in it beyond the initial look into the record. They have done very well by that.

Mr. PREYER. Well, without objection, that material will be made a part of the record.

[The information follows:]

BEFORE THE OCCUPATIONAL SAFETY
AND HEALTH ADMINISTRATION OF THE
U.S. DEPARTMENT OF LABOR

SUPPLEMENTAL COMMENTS BY PUBLIC CITIZEN'S HEALTH RESEARCH GROUP
ON PROPOSED RULE GOVERNING ACCESS TO EMPLOYEE EXPOSURE
AND MEDICAL RECORDS [29 CFR 1910.20]

MARCH 30, 1979

Public Citizen's Health Research Group is a non-profit, public-interest organization engaged in advocacy and research concerning health issues, including occupational safety and health. HRG wishes to record the following supplemental comments concerning the proposed rule governing "Access to Employee and Medical Records," [29 CFR 1910.20], published at 43 FR 31371, July 21, 1978.

I. Record Preservation

The proposed rule would require employers to preserve and retain records "for at least the duration of the affected employee's employment with the employer plus five (5) years, except where a specific occupational safety and health standard provides a different retention period." 43 FR 31374.

In our September 22, 1978 comments on the proposed rule, HRG maintained that this proposed retention period was too short. HRG called for a retention period equal to the duration of employment plus 25 years. On January 4, 1979, at public hearings on the proposed rule, HRG noted that its written comments were in error and should be corrected to call for a retention period equal to the duration of employment plus 40 years. HRG would like to take this opportunity to submit, for the record, arguments and data supporting this position.

As we noted in our September 22, 1978 comments, many of the gravest occupational diseases, become manifest many decades after employee exposure to a substance. In order to document cases of occupational disease caused by exposure to carcinogens and other substances with long latency periods, OSHA and NIOSH scientists will need to examine exposure records long after the brief retention period in the proposed rule. In addition, persons who contract diseases caused by exposures to these substances will need to gain access to their exposure and medical records long after the period proposed in the rule.

HRG supports a retention period equal to the duration of employment plus 40 years because the medical literature demonstrates that this₁ latency period is characteristic of many occupational diseases.

For example, cancers caused by occupational exposure to arsenic, nickel, chromates, ionizing radiation and aromatic amines can become manifest 40 or more years after exposure.₂ Studies have shown that

diseases linked to exposure to other substances also become manifest after long latency periods, e.g., asbestos (20-25 years from onset),³ vinyl chloride (15 years),⁴ tar fumes (9-23 years),⁵ crude paraffin oil (3-35 years).⁶

As Dr. W.C. Hueper, and Dr. W.D. Conway wrote in their classic text, Chemical Carcinogenesis and Cancers, "The onset of a carcinogenic exposure may antedate by many years or even decades, the appearance of the first symptoms of a cancer causally related to it. The establishment of direct associations between such events is not infrequently obscured by the fact that the critical exposure to a carcinogen may have ceased months-to-decades before the cancer becomes manifest, i.e., an exposure-free and symptom-free lag period may intervene."⁷

In light of the fact that many occupational diseases only become manifest decades after initial exposure to the causative substance, a regulation which permits employers to destroy employee medical and exposure records 5 years after the period of employment will hardly provide employees, their representatives, OSHA or NIOSH with the kind of information they need to carry out the purposes of the Occupational Safety and Health Act of 1970. In fact, a rule which permits employers to destroy records which would help employees, their representatives, OSHA and NIOSH to understand the cause and nature of occupational diseases would violate the Act.

Section 8(c)(3) of the Act requires the Secretary of Labor to promulgate regulations permitting "each employee or former employee to have access to such records as will indicate his own exposure to toxic materials or harmful physical agents." 29 U.S.C. §57(c)(3). On its face, this provision clearly does not permit the Secretary to limit access to only those records retained 5 years after the period of employment. If an employer has any records which indicate an employee's or former employee's "exposure to toxic materials or harmful physical agents," Section 8(c)(3) requires the Secretary to promulgate regulations guaranteeing access to those records.

The legislative history of Section 8(c)(3) supports this reading of the provision. The portion of Section 8(c)(3) concerning employee access to exposure records is identical to language contained in the Senate version of the Act. In offering the Senate bill, Senator Harrison Williams, the bill's chief sponsor, declared:

A particularly urgent concern repeatedly brought out during our hearings is the frequent exposure of many workers to a great variety of toxic materials or harmful physical agents. They are often unaware of the nature of such exposure or of its extent. In some cases, the consequences of overexposure may be severe and immediate; in other cases, effects may be delayed or latent.

In all of these situations it is important that the worker be adequately protected against excessive exposure to fumes, gases, dust, or other substances determined to be harmful, and equally important that he be aware of any such hazard.

Accordingly, our bill provides that standards dealing with toxic materials or harmful physical agents shall make suitable provision for...monitoring by the employer of levels of employee exposure. In addition, employees would have access to the records of such monitoring.

Plainly, Congress intended that the Secretary issue regulations requiring employers to grant employees and former employees access to all records which indicate exposure to harmful substances--including those substances which have "delayed or latent" effects. A regulation which bars former employees from gaining access to records after the fifth year following employment violates the Congressional intent.

Clearly, the medical evidence and statutory language requires OSHA to lengthen the retention period contained in the proposed rule. Specifically, OSHA should extend the retention period to the period of employment plus at least 40 years. For the record, HRG is attaching copies of the medical literature referred to herein.

II. Access for Employees and Former Employees

In our September 22, 1978 comments, HRG strongly supported those portions of the proposed rule which assure employees and former employees access to exposure and medical records made by, maintained or accessible to employers. HRG took this position, in part, because such access to employee records will increase employees' awareness of workplace hazards and help employees and former employees recognize symptoms of work-related illness. If employees and former employees learn from their medical or exposure records that they have been exposed to a hazardous substance or have been diagnosed as suffering an occupational disease, they can then seek appropriate medical attention, arrange for a NIOSH investigation, or request an OSHA inspection. Without the knowledge available in the medical and exposure records, however, employees and former employees have no way of knowing whether they are at risk.

On February 4, 1979, CBS News broadcast a report on "60 Minutes" which highlighted the need for employee and former employee access to medical and exposure records. The report, entitled "Brown Lung," revealed that textile workers who had been examined for pulmonary disorders by company physicians were unable to learn the results of the examinations. In one case, the report revealed that a company's medical records showed that an employee had been diagnosed as suffering from "a possible degree...of byssinosis," but the employee was never informed of this fact.

The "60 Minutes" report provides compelling evidence of the importance of a regulation which permits employees and former employees to have access to their medical and exposure records. If the workers interviewed by CBS had been able to obtain their records, they would have been able to seek medical attention or transfer to a less dusty work environment. Thus, such a regulation would have served to reduce a serious occupational health

hazard at minimal cost to the government or employee.

Since the "60 Minutes" report provides an excellent and current example of the kinds of problems the proposed rule can solve, HRG is submitting the text of the report for the record. In addition, HRG wishes to incorporate by reference comments filed today by the Carolina Brown Lung Association, which also demonstrate the need for a rule giving employees and former employees access to medical and exposure records made by, in-tained or accessible to employers.

HRG appreciates this opportunity to submit additional comments on the proposed rule and urges OSHA to carefully consider the serious question of public policy raised herein.

FOOTNOTES

1. Hueper and Conway, Chemical Carcinogenesis and Cancers (Springfield, Ill. 1964), p. 43.
2. Ibid.
3. Hiatt, Watson and Winsten, eds., Origins of Human Cancer, Book A (Cold Spring Harbor Laboratory 1977), pp. 148, 152, 484.
3. Hiatt, Watson and Winsten, eds., Origins of Human Cancer, Book A (Cold Spring Harbor Laboratory 1977), p. 1775.
4. Ibid., p. 1800.
5. Hueper, op.cit.
6. Ibid.
7. Hueper, op. cit., p. 42.

Mr. PREYER. On the question of whether the institutional review board is the right organization to review and approve access to medical records by researchers, you mentioned that these boards would be adequate, I believe that is the word that you used.

Is there any better approach to it than having an institutional review board? Do you have any suggestions of how that could be improved?

Dr. WOLFE. Well, I think some of the suggestions are enclosed in the testimony that I gave to OSHA. If, for example, the people doing the epidemiological research are researchers in the National Cancer Institute and the National Institute of Occupational Safety and Health, OSHA, et cetera, they should all be governed by a pretty much identical set of guidelines that allow them to do only this and that. I think that could complement the institutional review board considerations.

If, for example, a study is being done at a hospital or under the guidance of an institutional review board on the use of certain drugs which does not necessarily fall under the OSHA-NIOSH and National Cancer Institute purview, then the same kinds of restrictions should be put on by the institutional review board.

In other words, once the institutional review board says OK, the access should be granted without consulting the patient. But those seeking the access should be, I think, constrained to the same kinds of procedures, deleting the personal identifiers when they have reached that point in the investigation that we are asking the Federal investigators to do.

Mr. PREYER. Let me ask a more general question which has been put to a number of witnesses by some members of our committee who are not here today so I will put it for them.

The question they have raised is, do we really need privacy legislation in this area? Have there really been complaints concerning it, or is it something that the Harris poll has discovered—a sort of genuine interest but one in which specifically it is hard to find examples of abuse?

You began by saying that your group has had many complaints from people in this area. How would you respond to the question of whether there really is any need for privacy in medical records legislation?

Dr. WOLFE. I mentioned that one of the main reasons we did this book "Getting Yours: A Consumer's Guide to Obtaining Your Medical Record" was to try and more comprehensively answer this really unending series of complaints that we had been getting and still are getting now.

The number, if anything, has increased rather than decreased. The response that we now give is to offer them a copy of this book. There is a clear trend in the last 5 or 10 years in this country. All of my medical colleagues that I went to medical school with or did internship or residency with or with whom I worked at the NIH before starting this group and who are now in private practice tell me that the biggest change that has occurred in the last 5 or 10 years in the health care system is that people are asking more questions, whether it is in the context of surgery, prescription drugs, or whatever.

The public is more curious now, and it is not true of everyone, but it is true of more people, and that is a comment physicians are making. Part of this is leading to increased informed consent for diagnostic and therapeutic procedures and, surgical opinions.

I think another example of this is the increasing tendency of people to wonder in general as well as in specific what their medical care is like as reflected in the medical record.

So I see this as part of the same trend, patients want to know more.

One of the positive benefits of this trend which has been documented in places where they do give out the records is that the patients have less anxiety about their illness and are better able to comply when it is appropriate, that is, when they are fully informed and the care makes sense, with the prescribed treatment.

So there is a need reflected not only by inquiries made to us, but there is the beginning of evidence that when patients are satisfied and patients are given their records, it is a positive rather than a negative force.

Remembering, of course, that those patients involved in malpractice kinds of legislation can get access anyway. Malpractice is an after-the-fact consequence after somebody has already been injured.

One would hope that getting access before those kinds of events have occurred might straighten out care that has been given to some people and prevent subsequent acts of malpractice.

Mr. PREYER. Thank you, Dr. Wolfe.

Mr. Kindness?

Mr. KINDNESS. Thank you, Mr. Chairman.

Thank you, Dr. Wolfe. We appreciate your appearing and testifying today.

Are you engaged in the practice of medicine at this time?

Dr. WOLFE. No; I am not engaged in the private practice of medicine.

Mr. KINDNESS. Was there a time when you were?

Dr. WOLFE. I was on the staff of the National Institutes of Health and spent 6 years involved in patient care. So in that sense I took care of patients. I was not out in my private office with my shingle hung up, though.

Mr. KINDNESS. In that context, did you have occasion to deal very much with patient records?

Dr. WOLFE. I certainly did.

Mr. KINDNESS. Were you ever in a position of managing that function, particularly having direct responsibility?

Dr. WOLFE. Certainly. In most of the patient care that I was involved in, it involved my making the medical record, keeping it and referring to it while the patient was in the hospital.

Mr. KINDNESS. I am having a little difficulty describing what I am getting at. I am trying to get the concept of whether you have dealt with the overall management of records in an institutional setting like that which I take it might very well be done perhaps by nonmedical personnel.

Dr. WOLFE. No; I was involved with patient care and records at the level of the doctor-patient relationship. I was not involved in the medical records divisions, which I think is what you are referring to, at the NIH.

It is interesting, though, that at the Bethesda Naval Hospital where I and members of my family received care while I was in the Public Health Service, patients are all given their records to carry from one place to another. I think that is a healthy trend. That is where it has begun in a sense in this country.

Mr. KINDNESS. In connection with the cost of this type of legislation, what I was trying to get at is whether you have made any appraisal or estimate of whether it would be more costly for some reason to maintain medical records, both in the case of the institutional setting and in the case of the individual doctor-physician in order to comply with the terms of such legislation?

I realize the dollar figures are not anything within the realm of possibility at this point, but is it your impression that there would be additional costs?

Dr. WOLFE. The only way that I can imagine additional costs beyond that for paying for the Xeroxing or SCMinig or whatever kind of machine you use would be if someone started keeping two sets of records.

That concept suggests, in the way it has been described to me sometimes, a threat by doctors of what might happen if we started requiring patients to get their records if they want them. But, otherwise, I see no additional costs.

I would just point to the present circumstance where upon initiating a malpractice case attorneys have access to the hospital and private practitioner records. What it amounts to is simply a Xeroxing of these records. Who pays for the Xeroxing is a different question. But I don't see any reason why.

You know, this is going to happen slowly as many things unfortunately happen in the health care system and elsewhere. We are not going to have 90 percent of the people rushing for their records. We are going to have a fair number of people doing it. It will be more than the number doing it now in the context of malpractice litigation. I think it is mainly going to be just a copying cost.

Mr. KINDNESS. But in terms of systems and record keeping, you don't see a significant problem that would arise?

Dr. WOLFE. No, other than one which I don't think is a problem. It is actually a hopeful thing. There is, as Dr. Weed has pointed out, an extraordinarily broad spectrum of carefulness, intelligibility or whatever, between good and bad medical records.

I think that the pressure that will be brought to bear by the possibility of disclosure of records is going to get a number of physicians to keep better records. For them that might create sort of a revolution in the sense that they are going to have to start organizing charts better than they have.

But I think that is a very good kind of thing. As it stands now, the records of a number of physicians not only are unintelligible to patients but are likely not intelligible to other physicians who might have to take over the care of those patients. Neither situation is a good one. I think the reform of medical records is going to be a certain accompaniment of this kind of access.

Mr. KINDNESS. When you were engaged in direct patient care with NIH, were you subject to any kind of policy or regulation with respect to the disclosure of information from patients records to the patients or to other persons?

Dr. WOLFE. I must say I was not aware of any. But, on the other hand, any time a patient asked me any information concerning what was in their record, I would tell them and in some cases I would show them that portion of their medical record that was relevant to it.

Mr. KINDNESS. What is your occupation at the present time?

Dr. WOLFE. I am the director of the Public Citizens Health Group. That is a private organization funded by contributions from individuals. We do work in occupational health, prescription drugs, and some issues having to do with health care delivery such as medical records.

Mr. KINDNESS. And in your practice or work have you ever worked with a hospital or hospitals so as to become familiar with their recordkeeping practices and what they did by way of disclosure to patients? Is there an example that we might know about from your experience there?

Dr. WOLFE. Well, I certainly have read the statements that have been submitted in the context of the Privacy Commission hearings by people representing the medical record keeping establishment.

There was a hearing in Los Angeles a couple of years ago, one of the series of hearings the Privacy Commission conducted. The day I testified, witnesses representing the Medical Records Association testified and described some of the problems that they have now in terms of access to records at a hospital level by attorneys and others representing people involved in litigation.

There is a mechanism set up, and as I said, I think a similar mechanism would be used. I have discussed several times with medical record keepers at hospitals this kind of problem.

So I think I am somewhat aware of what the issue is now and what it might be when such a provision was passed.

Mr. KINDNESS. Are you aware, as a result of that experience, of any material and substantial reticence about such legislation as this?

Dr. WOLFE. Well, I think that if the medical record people believe, as some do, that passing this would cause the majority of patients to come rushing for their record, there would be a logistic nightmare for them. They have raised that possibility.

As I said, I don't think that kind of thing is going to happen. I think a number of people will get their records, but it will be more in the order of those getting it now or several percent as opposed to the majority.

I think that whatever gearing up that needs to be done for that will happen, without really disruptive kinds of efforts.

Mr. KINDNESS. In preparing your guide, did you have occasion to survey the State laws that are in existence? There was mention in your testimony of Virginia and some others.

Dr. WOLFE. Yes. There is a chart that goes from pages 20 through 23 that reviews State by State the access laws, cites the statute, whatever case law, if any, has been brought under the statute that has been cited, what kind of records are covered and a number of other things, qualifications and things that are specific about the State laws.

So it is all reviewed in there. It is current as of July 1978.

As we mentioned in the book, at the time that this was finished there was still legislation pending in a number of States. The trend is clearly on the increase, but at the present time it might take another 20 or 30 years or so for all the States or even most of them to grant access. Most of them now still do not grant access even with the few changes that have occurred since last summer.

Mr. KINDNESS. I wonder if you would be willing to submit a copy of that for the record?

Dr. WOLFE. It is already a part of the record. But we have an extra copy here if you would like it for yourself.

Mr. KINDNESS. Thank you.

In the event there is Federal legislation in this area, and there are, of course, variations between States as to the provisions of their laws and their statutory law and their case laws, would it be inappropriate, in your view, to have a mechanism in the legislation that would allow those State laws that meet certain standards of established criteria of some sort to remain the controlling law in that State?

Dr. WOLFE. Yes; I would certainly support that, particularly, as I said, if the legislation that passes is limited to disclosure of institutional records and a particular State not only grants access to that, but also to individual doctor records.

Mr. KINDNESS. Ohio doesn't show up in here.

Dr. WOLFE. I am from Ohio, too. I was disappointed in that.

Mr. KINDNESS. The opposition that you expressed to section 123 of the bill, I would like to follow that just a little further.

Would you oppose giving relatives information about a patient or his condition and location in a hospital?

Dr. WOLFE. Under section 123?

Mr. KINDNESS. Well, in that general context.

Dr. WOLFE. Well, we mentioned in the context of section 111, if the subcommittee decides to deny direct patient access and provides discretion, that the patients should be allowed to choose whoever they want to get the access.

It is underlined that we oppose the denying of direct access. If that person chosen by the patient would be a member of their family or a friend, that under those circumstances those people should be able to get access.

Mr. KINDNESS. I see.

I might just mention that the content of section 123 which reads that a medical care facility may disclose a medical record it maintains about an individual without the authorization described in section 115(A) if the disclosure only reveals the presence of the individual at the facility or the provision of services to the individual at the facility or the provision of services to the individual at the facility, his location at the facilities and his general condition, and the individual has not objected to the disclosure and the information does not reveal specific information about the individual's condition or treatment.

Now, I thought I understood that that section was objectionable in your view. What about as applied to relatives?

Dr. WOLFE. The answer I gave you was in the circumstances where the family, friends could get disclosure as mentioned under 111. As it was said here in section 115, the patient has not objected

to the disclosure, and that in no way insures that the patient has knowledge of such a pending disclosure.

In other words, the absence of objection does not mean the patient has been informed and that they would seek disclosure if it was sought. Disclosure of the sensitive fact that a patient was receiving attention for some general condition should occur only after an individual has given informed and voluntary consent.

So I would make it a more active kind of thing rather than saying you just didn't object. The way it is worded, the patient might object because that possibility was not presented to them.

Mr. KINDNESS. Do you have some background or training in law, too?

Dr. WOLFE. No; I do not.

Mr. KINDNESS. I was a little curious about your tie.

Dr. WOLFE. Those are crossed quills and ink bottles, which are part of a bicentennial tie.

Mr. KINDNESS. It is a very handsome tie.

Dr. WOLFE. Thank you very much.

Mr. KINDNESS. Thank you, Dr. Wolfe, and thank you, Mr. Chairman.

Mr. PREYER. Thank you.

Dr. Wolfe, you have made a number of interesting points which I don't think we will have time to discuss at length today. For example, your comments about section 111(b), I think, are very interesting, and that is a very troublesome area.

Let me just ask one question in that regard. Do you think if we eliminated that section, as you suggested, that it would have an effect on the records which doctors keeps? Would they be less than frank in keeping their records in the future if they know there is no stopgap, fallback provision for them? A psychiatrist, for example, or a doctor who may wish to put personal comments preferences into a patient's history or something of that sort? Are you going to have a double standard in effect, two sets of records that doctors would keep?

Dr. WOLFE. I don't think that this legislation, even if amended as we suggest, is going to create that where it doesn't already exist.

I am told, and the talk comes more out of psychiatric circles than anywhere, I am told by a number of psychiatric practitioners that now, simply because of the possibility of litigation, whatever, that they do in some cases keep two sets of records. Whether that is legal is another matter. I suspect it probably isn't, but I don't think there is going to be necessarily any more of that if this kind of provision passes.

The psychiatrists, on one hand, are perfectly glad to consider their treatment part of the health care system, and receive in this case Federal funds under medicare, medicaid for it, and yet somehow they think their records and the way they practice should be distinguished from that of other people giving medical care. I disagree with that.

Mr. PREYER. I agree keeping two sets of records is not a practice that we want to encourage. I should think the medical profession would vigorously object to that kind of thing.

Dr. WOLFE. I would, too, but they haven't, and, as I said, apparently it has gone on and is going on in certain quarters, and I hope it stops.

Mr. PREYER. Let me ask one other question. Our bill would permit the use of auditors to have access to medical records without the consent of the patient. Do you object to access by auditors?

Dr. WOLFE. Are you speaking of auditors in the context of epidemiological research?

Mr. PREYER. Well, I think the context is financial auditors, and, frankly, one of the problems is when is it a financial audit and when is it an investigation? I wondered if you had any objection to access by financial auditors?

Dr. WOLFE. I can narrowly answer the question. In section 129, where I suppose financial auditors would be one of the kinds of people who would be involved in fraud and abuse investigations, and, as we state, we don't believe that it is necessary for such purposes to know the identity of the patient that identifiers could be put. I don't know what other kind of financial audits are done. Most of the ones that I can think of would have to do with fraud and abuse.

Right now, Blue Shield, acting as fiscal intermediary for medicare knows a given person during a period of time amasses a certain amount of bills under medicare, and that is kept under lock and key. Again, there are no instances I am aware of where that has been disclosed. It is in a computer and has guarded access. That is a second form of financial oversight or auditing beyond fraud and abuse that is done. It doesn't need, beyond a certain point, the name of the patient.

Mr. PREYER. I think a troublesome point arises if you assume a financial audit is justified. At the point where the audit evolves into an investigation or potential prosecution, the patient probably ought to know about it. Where to draw the line, is difficult. You can't just rely on not having a patient identifier in one place when identification is necessary if you are moving toward prosecution.

Dr. WOLFE. It is difficult to imagine the kind of circumstances where notifying the patient would be necessary. Presumably, the financial audit would reveal unnecessary treatment or treatment that presumably was given when, in fact, it wasn't given. I would have to see some specific examples of this before really commenting beyond what we said as far as fraud and abuse.

Mr. KINDNESS. Mr. Chairman, I just had one other question.

Dr. Wolfe, I noted in your testimony the reference to the deletion of any identifiers with respect to research projects after the records have been selected.

Do you have any comments about followup studies over a period of time, and what problems are presented there by not having the identification of the individual?

Dr. WOLFE. You mean followup studies by the same epidemiologists?

Mr. KINDNESS. Right, in order to determine what occurs over a period of time with a particular patient.

Dr. WOLFE. Well, assuming that the records upon which the original round of investigation was made are still there, they go through the process again, I would imagine.

Mr. KINDNESS. Is that an assumption that you would make, say, over a 20-year period?

Dr. WOLFE. I think one could. On the other hand, I suppose—if the epidemiologists get the initial batch of data, have looked at the records, have the patients' identification and what happened to them, the outcome of the drug, occupational exposure, whatever, to strip off the identifiers and from that point in their own investigation they use data that doesn't have any personal identifiers, I suppose storage of identifiers could occur, particularly as we are getting more and more computerized records. These could be stored in such a way during the first round of investigation so that those who were doing the studies don't know the names, but retrieval could be made easier 20 years down the road.

Mr. KINDNESS. Thank you.

Dr. WOLFE. I know, for example, that in a number of prepaid group plans—some of the larger ones, such as in New York—all of this data is computerized, and a lot of these people are working in industries where there are some adverse occupational exposure. They have done at different intervals searches of the record for anemia and people exposed to lead, and they have gone to the computer, gotten what they need, stripped the identifiers, done the study, and 5 years later go back again and get the followup information. So I don't really see any difficulties necessarily with that.

Mr. KINDNESS. That would seldom be done with the records of individual physicians, I suspect. Largely that would be done from an institutional record system?

Dr. WOLFE. Yes, if one were doing an epidemiological study in a given study a particular physician might have none or one or two patients who were in the group that was the subject of that study, and they would simply go to the physician and get those records. It might be 20 years down the line that same person wasn't even under the care of that physician, so they wouldn't bother going back there for the subsequent investigation.

Mr. KINDNESS. And the record might not be there in a private physician's custody at that point possibly?

Dr. WOLFE. You mean 20 years later. It may have been transferred to another physician. It is much easier to do these studies if they involve records of patients that were compiled in a hospital rather than in a private doctor's office. That is one of the biggest thorns in the side of these sources of studies now, even the first round.

Mr. KINDNESS. Thank you.

Thank you, Mr. Chairman.

Mr. PREYER. Thank you very much, Dr. Wolfe, and we look forward to keeping in touch with you as this legislation develops.
[Dr. Wolfe's prepared statement follows:]

TESTIMONY ON H.R. 2979, THE FEDERAL PRIVACY OF
MEDICAL RECORDS ACT

BEFORE
THE SUBCOMMITTEE ON GOVERNMENT INFORMATION AND INDIVIDUAL RIGHTS
OF THE
HOUSE COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE

BY THE
PUBLIC CITIZEN HEALTH RESEARCH GROUP
SIDNEY M. WOLFE, M.D., TED BOGUE, AND DAN SIGELMAN

JULY 9, 1979

Chairman Preyer and Members of the Subcommittee:

Thank you for the opportunity to present our views on the access to and privacy of patient medical records.

In August of 1978, the Health Research Group (HRG) published Getting Yours: A Consumer's Guide to Obtaining Your Medical Record,* which contains a discussion of what is in a patient's medical record and why access to it is important, a state-by-state description of medical record access laws, and a step-by-step guide for patients to getting and using their own medical records. A copy of this guide is being submitted for the record with this testimony.

Getting Yours was prompted by the many complaints we received from consumers who were surprised to learn that their physicians or hospital had denied them access to their own medical records. As described in the Guide, in 14 states and in Federal facilities patients do have a right of direct access to records held by doctors or hospitals or both. In most states, however, it is much easier for patients to get their CIA or FBI files than to obtain their medical records. Doctors and hospitals can refuse access altogether with impunity or tell the patient only what they want him or her to know.

Freer patient access to their own medical records could have a profound impact on the health care system. Medical record expert Dr. Lawrence Weed of the University of Vermont states that it "may be the most effective weapon we have against over-utilization of medical care, with its dangers to society--mentally, physically, and economically." The transmission of information from physicians to patients about medical conditions and treatment will improve therapy through better communication, understanding, and compliance with treatment plans. 2

Patients can avoid expenses and medical risks by relying less on their physicians and more on their own participation in preventing and treating illness and injuries. Drs. Vickery and Fries have estimated that 70% of all outpatient visits to physicians are unnecessary.**

* For a copy of Getting Yours, send \$2.50 to Health Research Group, Dept. HR, 2000 P Street, N.W., Suite 708, Washington, D.C. 20036. Discounts are available on bulk orders.

** Vickery, D.M., Fries, J.F., Take Care of Yourself: A Consumer's Guide to Medical Care.

-2-

Finally, patients cannot safeguard their privacy rights unless they know the contents of their medical records and consent to their release to third parties only when they think it appropriate or when a genuine and substantial public interest demands it.

Doctors and hospitals opposed to free patient access say that patients won't understand the records, that record-keeping will suffer, and that too much information might be "harmful" to patients. In fact, they may really be saying that they won't take the time to talk to their patients, that they might be embarrassed by the poor quality of their records (or their treatment), and that they want to keep patients ignorant and dependent on them. (4)

This philosophy of "doctor always knows best" not only is patronizing to patients but serves as a cover for a more fundamental doctor discomfort. Testifying before the Privacy Commission, Dr. Joseph Boyle, an AMA official and formerly head of the California Medical Association, said that patient access to records "could result in numerous cases of harm." He could give no specific examples. Boyle added, by way of general example, that "some individuals, upon seeing their records, might decide to treat themselves." That's true. If people could see their medical records and discover the basis (or lack thereof) for various drugs or operations, they might well treat themselves and be better off for it. In fact, most visits to the doctor are for diseases less dangerous than the drugs used to treat them.

Getting Yours reviews several studies which show that, rather than being "harmful" to patients, routine patient access to medical records actually enhances patient compliance with physician recommendations for medications and other therapy, reduces patient anxiety about medical care, and often leads to the adoption of healthier patterns of living.

When our consumer guide was published we called upon HEW Secretary Califano and members of Congress to support Federal legislation which would grant all American citizens an unrestricted right to access to their own medical records. Secretary Califano and several members of Congress have endorsed Getting Yours and urged that such consumer information be broadly disseminated to the general public.

Thus, the Health Research Group is pleased that Congressman Preyer and other members of Congress have introduced H.R. 2979 and other bills which recognize a general right of patient access to medical records. However, we oppose several provisions of H.R. 2979 which unnecessarily restrict access. In the balance of this testimony, we will make several suggestions for strengthening these provisions and will comment on those sections describing the circumstances under which researchers and others can obtain access to medical records without individual patient consent.

-3-

COVERAGE SHOULD BE EXPANDED TO INCLUDE RECORDS
HELD BY PRIVATE PHYSICIANS

→ ^{see} ~~and~~ see absolutely no justification for confining the right to patient access to institutional medical records, and excluding records maintained by private physicians. Such a restriction would prevent patients from gaining access to records concerning by far the most frequent type of medical treatment--the physician-patient encounter in a private office. In 1976, the ratio of non-institutional physician visits to hospital admissions was more than 28 to 1.* Similarly, there were approximately 10 times as many non-institutional physician-patient encounters as hospital outpatient visits, which includes both emergency room and ambulatory clinic visits.** In addition, we have found that hospitals are more likely than physicians to afford patients access to their own records in states where access is not required by law.

Consequently, by excluding private physicians, the bill ignores the overwhelming majority of medical records to which patients have been denied access. We recommend that permitting a patient access to his own medical records and a right to make corrections be made a condition of physician as well as institutional participation in Medicare and Medicaid.

We also strenuously object to Section 111(b), which allows medical facilities to deny patient inspection if they determine that "inspection might reasonably be expected to cause sufficient harm to the individual so as to outweigh the desirability of permitting access." In the virtually unfettered and vaguely stated discretion it grants providers to refuse patient inspection, this provision creates an exception which potentially swallows up the general rule stated in Section 111(a)(1) that "a medical care facility shall permit an individual to inspect any medical record that the facility maintains about the individual."

In its extensive public hearings on access to medical records, the Privacy Protection Study Commission found that "not one witness was able to identify an instance where access to records has had an untoward effect on patient's medical condition." As noted above, studies have shown just the opposite effect.

Even if the bill could identify and describe more specific circumstances under which patients access might be inappropriate, creating an exception to access would be undesirable. Patients denied access for such reasons would be likely to engage in anxiety-producing and therapeutically counterproductive speculation about the reasons underlying nondisclosure. If the patient successfully inferred from a limited list of statutory exceptions the provider's

* Socioeconomic Issues of Health 1978, Center for Health Research and Development, AMA, pp. 177, 187.

** Id., p. 179.

-4-

basis for nondisclosure, the intent behind denying inspection would have been seriously frustrated. On the other hand, a set of specifically enumerated criteria for non-disclosure might prompt erroneous patient speculation, which would be equally inimical to a healthy and productive physician-patient relationship.

Thus, we are convinced that specifically stating such criteria would be an unsatisfactory response to the problem of overbroad discretion and we reject any paternalistic attempt to "protect" the patient from his own medical records. Section 111(b) should simply be removed from the bill.

If the Subcommittee nevertheless decides to deny direct patient access at the provider's discretion, the "appropriate person" designated by the patient to inspect the records on the patient's behalf should be broadly defined--i.e., the patient should be allowed to choose whomever he or she wishes and to communicate freely with that person about the content of the medical record.

This position is similar to that of the Privacy Protection Study Commission which said, "in no case, however, should the physician or other keeper of the record be able to refuse to disclose the record to the designated responsible person, even when it is known in advance that the designated person will give the patient full access to it."*

The implication of placing barriers in the way of those seeking their medical records has been well stated by Ed Mulligan of Syracuse, N.Y., a leader in the battle to obtain unrestricted access to medical records: (5)

"A society that denies a person knowledge of his own state of health is toying with tyranny and is able to maintain this censorship only because in general the victims are weak, sick, alone and helpless."

Copy - FEDERAL LEGISLATION OR STATE LEGISLATION ON
ACCESS AND CONFIDENTIALITY? 6

HRG is persuaded that Federal legislation is needed to ensure a uniform approach to medical records access policy. Reliance on a state-by-state approach would subject highly mobile patients--especially those seeing a physician in a state other than that in which they reside--to the vexing irregularities of varying state laws governing patient access to medical records.

For example, while Maryland and the District of Columbia have no statutory or case law which gives patients a right of access, the Code of Virginia specifically confers upon patients the right to copy both their physician and hospital medical records. Absent a federal standard governing access to such records, whether a patient has a right to inspect them wholly depends on where he or she decides to seek medical care. Such a basic right should be assured for all U.S. citizens.

* Commission Report, p. 298.

-5-

PUBLIC DISCLOSURE OF PATIENT RECORDS

HRG opposes Section 123 which permits a facility to disclose a patient's medical record without authorization "if the disclosure only reveals the presence of the individual at the facility or the provision of services to the individual at the facility, his location in the facility, his general condition, and--

- (1) the individual has not objected to the disclosure, and
- (2) the information does not reveal specific information about the individual's condition or treatment."

We believe that unauthorized disclosure of the fact of institutional treatment as well as a patient's general condition, even while not disclosing "specific information about the individual's condition or treatment," nonetheless constitutes a substantial invasion of a patient's personal privacy. That the patient "has not objected to the disclosure" in no way ensures that (1) he has knowledge of such an impending disclosure and (2) would consent to disclosure if permission to disclose were sought. Disclosure of the sensitive fact that a patient is receiving medical attention for some "general condition" at a particular facility should occur only after an individual has given his informed and voluntary consent.

ACCESS FOR RESEARCHERS

We support Section 124 which affords access to medical records without specific patient consent for the purposes of Health Research. The record of epidemiologic investigators--the principal kind of health researcher needing such access--is excellent in strictly confining the use of medical records to legitimate research purposes while protecting patient privacy. A requirement of notification or consent by the patient before gaining access to each individual record would render epidemiological research virtually impossible.

The requirements of Institutional Review Board approval, removal of patient identifiers, and other restrictions on use are adequate, in our view, to assure protection of patient privacy. We would suggest, however, that the notice described in § 124(c), which must be provided to the researcher, also include notice that failure to adhere to the restrictions on use can result in a civil lawsuit by an aggrieved patient.

DISCLOSURE FOR FRAUD AND ABUSE INVESTIGATIONS

271 ~~HRG~~ believes that Section 129 (a)(1)(A) which provides for disclosure of patient records to government authorities for use in an investigation or prosecution of fraud, abuse or waste should be amended to require the deletion of all patient identifiers. ~~HRG~~ *we* can conceive of no circumstances in which the identity of individual patients is crucial to the investigation and prosecution of fraudulent or wasteful Federally-funded medical care practices. ~~HRG~~ *we* urges that identifiers be removed from such records in a fashion similar to that called for in Section 125(b)(2), a provision relating to disclosure of medical records for audit or evaluation purposes.

Thank you and we would be happy to answer any questions.



**GETTING YOURS:
A CONSUMER'S GUIDE
TO OBTAINING
YOUR MEDICAL RECORD**

**BY
MELISSA AUERBACH
AND
TED BOGUE**

ACKNOWLEDGEMENTS

My thanks to all of those who helped in the preparation of this handbook: to Ted Bogue for his continuing guidance and editorial assistance; to Dr. Sidney Wolfe, whose idea it was to write this book and who offered many suggestions along the way; to Colette Thomas, who patiently oversaw all of the clerical work involved in completing the book; to Frances Bell, who typed from an illegible manuscript; to David Shingler for getting the book printed; and to the many others who provided us with information.

July 1978

Melissa Auerbach

Third Printing, June 1979

Copyright © 1978 Public Citizen's Health Research Group

All rights reserved. No part of this book may be reproduced or utilized in any form or by any means electronic or mechanical, including photocopying, recording, or by any other information storage and retrieval system, without written permission from the author. Those who wish to obtain or reproduce large quantities of this book should contact the Health Research Group, 2000 P Street, N.W., Suite 708, Washington, D.C. 20036. Permission will be granted in appropriate circumstances.

TABLE OF CONTENTS

Introduction	11
I. Importance of Access	1
A. Why Would You Want To See Your Medical Record?	1
B. What Is In Your Medical Record?	1
C. Advantages of Patient Access	1
D. Objections by Doctors to Free Access	4
Notes	7
II. A Step-By-Step Guide to Getting Your Records	10
A. Overview of the Laws	10
B. How To Get Your Records	10
C. How To Use Your Medical Records	13
D. How To Get the Law Changed	14
Notes	17
III. State-By-State Survey of Laws	18
A. Guide to the Chart	18
Chart	20
B. State-By-State Narrative	24
IV. Obtaining Medical Records In Federal Facilities	34
A. Your Right to Access Under the Privacy Act	34
B. Variations in Procedures Among Agencies	34
C. Making a Request	34
D. Time Requirements, Fees, Appeals	35
E. Amendment or Expungement of Records	36
F. Freedom of Information Clearinghouse	36

INTRODUCTION

It usually is extremely difficult for patients to get to see their own medical records. Despite the importance to the patient of the information these records contain, doctors, hospitals, and other health care providers generally resist patient access. This book will tell you how to proceed in an attempt to get your medical record. The first section deals with the importance of patient access. It tells you what to expect to find in a medical record, discusses the advantages of access, and demonstrates the fallacies in doctors' objections to access. The second section is a step-by-step guide to getting your record. It contains an overview of the law, tells you how to proceed in requesting your records, tells you how to use these records, and suggests how you might work to change the law in your state so that it provides for freer patient access. In the third section, you will find a state-by-state survey of laws concerning patient access. The fourth section discusses the Federal Freedom of Information Act and Privacy Act, which govern patient access to records held by Veterans Administration Hospitals, Public Health Service facilities, and military hospitals under the Department of Defense.

I. IMPORTANCE OF ACCESS

A. Why Would You Want to See Your Medical Record?

Seeing your record will make you a more informed patient; help you establish a more open physician-patient relationship; provide you with continuity of care when you change doctors; and help you protect your privacy by allowing you to see and correct information that will be passed on to others. (Advantages of patient access are discussed more fully in part C below.)

B. What Is In Your Medical Record?

A medical record may be brief or may run on for hundreds of pages. (1) Depending on your reasons, you may want to see only part of it. A standard hospital record contains a face sheet with information such as your name, address, employer, and insurance coverage. An admission work-up records your condition at the time you were admitted to the hospital, including symptoms and initial tests. Progress notes describe further tests, treatment, and your daily care. An operative report contains a surgeon's detailed account of any surgery you have had. A pathology report is an analysis of any tissue removed during surgery or in a biopsy. An x-ray report is a radiologist's account of any x-rays you have had. Laboratory reports include results of blood tests, EKG's, EEG's, etc. Vital sign sheets are graphs of your temperature, blood pressure, pulse and respiration. Doctor's order sheets are a doctor's directions to a nurse regarding tests, treatments, and medication prescribed. A discharge summary reports your diagnosis and condition at the time of discharge and indicates medications and treatment prescribed for the future. (2)

A doctor's record may be briefer, but should include personal and family data and information on symptoms discovered, test results, and treatment and medications prescribed.

C. Advantages of Patient Access1. Protecting Your Privacy by Being Informed

The Executive Director of the American Medical Record Association suggests that "a complete medical record may contain more intimate details about an individual than could be found in any single document." (3) You may, thus, cringe at the idea of anyone else's being allowed to delve into your records. A fact of life in the seventies, however, is that

medical records "are widely shared with health insurance companies, government payers, law enforcement agencies, welfare departments, schools, researchers, credit grantors, and employers." (4) What someone else gleans from your file may affect your opportunities for education, employment, or government benefits.

Most states have laws protecting the physician-patient privilege, which protects against the disclosure of medical information by a physician in legal proceedings. (5) Thirty-one states further limit third party access in other contexts by separate statutory provisions or by specific exemptions to the public records provisions of freedom of information laws. (6) These laws, however, do not by any means guarantee confidentiality. The physician-patient privilege is often waived by the mere filing of a suit in which the patient's physical or mental condition is at issue. (7) Privilege and confidentiality laws generally do not apply to non-physician health personnel (who often have routine access to patient records) and many states have no laws limiting non-judicial disclosures. Patients are usually poorly informed about the extent of the disclosure they are authorizing and often consent in order to obtain some indispensable benefit (such as life insurance). Finally, there are deplorable examples of unauthorized disclosure. (8)

Even when a patient's consent is required for third-party access, however, you can hardly be expected to make an informed decision as to whether or not to authorize such disclosures when you have only the vaguest idea of just what will be disclosed. (9) Moreover, only if you are able to see your own record before allowing anyone else to can you correct any mistakes in the data relating to family and personal histories, or even diagnosis (especially in psychiatric cases), so that the record released to others will be an accurate one. (10)

2. Improved Patient Education

Seeing your medical record would allow you more fully to understand your medical condition. Only armed with such understanding can you evaluate the risks and benefits of, and make an informed decision as to whether or not to consent to, proposed treatment. (11) The doctrine of informed consent in malpractice law dictates that a patient has the right to know about his condition, why a certain treatment is proposed, the possibilities of success or failure, any expected side effects, and any possible alternatives.

Patient access to medical records would help assure truly informed consent. It would enable you to take your medical history into account when making decisions that affect your health care. If, for example, your record showed that you had had an allergic response to a certain drug in the past,

you would know not to consent to its use in the future. If it is discovered, after you have been treated, as in the case of DES, that a drug may have produced ill side effects, you should be entitled to examine your record to determine whether you were given that drug.

If you appreciate the state of your health, you may be better able to take proper precautions in the future and to monitor the course of your own condition. Studies indicate that a patient who understands her medical problem and treatment is more likely to comply with physicians' orders. (12) The Given Health Care Center at the University of Vermont conducted an experiment in which patients were given copies of their own records. Responses to questionnaires mailed to one hundred consecutive patients revealed that, after seeing their records, 84% of the patients were much more careful about following specific recommendations for medications. 78% had made changes in their patterns of living, eating, or drinking, and 97% said that they worried less about their health care after reviewing their own records. (13)

In Boston, Massachusetts, the Beth Israel Ambulatory Care Center conducted a pilot project in which providers and patients "shared" the medical records. They developed a problem list and authored the record jointly. Preliminary observations indicated an increase in patients' knowledge relating to their medical condition and treatment, patient satisfaction, and an increase in patients' confidence in making judgments and choices regarding their health care. (14)

A family physician in Indiana recently wrote a medical journal article entitled "I make my patients be their own doctors." Treatment and education go hand in hand in his practice: "Once a patient understands the alternatives he has available for his illness, he can make his own decision and plan his own cure. The good things we doctors accomplish with patients are accomplished only with their entire assistance." (15)

3. A More Open Physician-Patient Relationship

Unrestricted patient access to medical records would likely transform the physician-patient relationship from one which is unequal, sometimes mutually suspicious, into one which is equal, open, and thus, more productive. Preventing free access will preserve the mystique of the doctor as a professional, an expert, a decision-maker, even a magician, while maintaining the patient in the role of a helpless, ignorant recipient of medical services. Kept in the dark, we, as patients, may justifiably be suspicious of the person who rushes us through tests and treatment while offering no more than a simplistic explanation of the problem diagnosed and the cure prescribed. For all we know, we may be kept in the dark as to the simple

fact that the doctor, too, is in the dark, and that all the tests are a cover-up for his incompetence, for the fact that the medical profession does not really have all the answers, or for the fact that we are not really sick. (16)

The physician should, finally, be recognized not as a demi-god administering cures but as a person with certain skills to offer. The patient must be recognized as a consumer of medical services who is entitled to be treated with openness and honesty as an equal.

Studies attest to the positive effects on the physician-patient relationship that would result from free patient access. The Beth Israel study on record "sharing" revealed that medical care providers, who were anxious initially, were more satisfied with patient interactions after patient access to records. (17) A study conducted at the Rehabilitation Medical Service of the Medical Center Hospital of Vermont evaluated the effect on patient-staff relationships of giving patients copies of their records. Staff members found that they could interact more freely and honestly with the patients, and the patient-staff relationship tended away from a paternalistic and caretaking one toward a more collaborative and educational one. (18)

4. Continuity

Patient access is a crucial prerequisite to quality health care in a modern, mobile society. Unlike the times not long ago when a patient may have stuck with one general practitioner (a kind of Jack-of-all-trades) for decades, most patients today will see many different doctors in the course of their lives. Population mobility and the specialization of medicine together have produced this change. While the rise of the specialist reflects the increased technical knowledge and applications of today's medicine, an unfortunate side effect is that doctors are less familiar with their patients. This means that a patient is required repeatedly to answer the same questions regarding her medical and personal history, to submit to tests that she has undergone before, possibly to be treated with drugs that have produced adverse reactions in the past. A patient, in going from one specialist to another or moving from one place to another, could go armed with a copy of her last medical record and be saved the wasted time and expense of repeat performances. And a doctor with access to a patient's previous care record could offer prompter, more complete, and better informed care. (19)

D. Objections by Doctors to Free Access

Given these advantages, why do so many in the medical profession oppose unrestricted patient access to medical re-

cords? The American Medical Association insists that an unlimited right of access to medical records "could result in numerous cases of inappropriate disclosure of medical information. For example, certain individuals upon seeing their medical records might decide to 'treat' themselves; other individuals with psychiatric problems could be seriously harmed by learning of information in their medical records. There is also the very real problem that medical information with complicated implications could be misleading or not informative without appropriate professional interpretation." (20)

1. Patients Won't Understand the Records

One reason often cited is that patients will be unable to understand the technical language of the medical record. (21) Many doctors may, in fact, hold up the spectre of incomprehensibly technical records because they would prefer not to have other doctors to whom the patient shows the records reading and commenting on their possibly sloppily-compiled memoranda. (22) Review of physicians' records by other physicians could benefit patients, however, as physicians would have more of a basis on which to judge the work of their peers and make informed recommendations when referring patients to other physicians. (23)

If records are too technical for a lay person to understand, then centers could be set up for the purpose of interpreting records and advising patients. This role could also be performed by a patient's rights advocate. George Annas, in his book The Rights of Hospital Patients, describes a patient's advocate as someone whose "primary responsibility is to assist the patient in learning about, protecting, and asserting his or her rights within the health care context." (24) In a hospital, for example, a patient advocate would, at the direction of the patient, have complete access to medical records and would be able to call in a consultant to aid or advise the patient. (25)

2. Time and Cost

Doctors and hospitals often argue that it would be time-consuming to have to explain the record to the patient and that a tremendous number of requests for records would greatly increase administrative costs. Any time spent in explaining records, however, would be more than compensated for in time saved in repeat questioning and testing. Moreover, encouraging the doctor to spend more time talking to patients would lead to more open relationships (see Part C-3 above). The reasonable cost of copying records could be charged to the patient.

3. Record-keeping Will Suffer

Doctors also insist that patient access would lead to a

decline in the quality and value of records, as doctors would hesitate to record mere speculations and would be forced to sacrifice directness and clarity for diplomacy. (26) A doctor who failed to record relevant information in a patient's record, however, would breach a duty of care owed the patient. Doctors should continue to record all relevant information and patients should be able to exercise their right to see such information if they so desire. Doctors should, moreover, be discouraged from the recording of irrelevant and pejorative information about the patient. Records will likely improve rather than deteriorate as doctors attempt to write them more clearly and carefully and stripped of irrelevant information.

4. Doctors' Prerogatives

When the question of medical record access arises, many doctors simply hide behind the old mystique: The doctor should be the one to decide. A patient should not, however, have to beg for access as a favor. She should be able to demand it as a right. The doctor is her agent, not her lord. Moreover, it is unfair to lay the patient at the mercy of a doctor or hospital whose interests may be adverse to those of the patient, as, for example, when the providers are trying to protect themselves against a malpractice claim. (27) Patient access to medical records would, in fact, lessen malpractice litigation, which now is often the only recourse a patient has of getting her records. The Secretary's Commission on Medical Malpractice found that "the unavailability of medical records without resort to litigation creates needless expense and increases the incidence of unnecessary malpractice litigation." (28)

5. Patient Harm

Doctors argue that access to the complete record may harm or alarm the patient, especially in the case of a psychiatric record or one containing a fatal prognosis. Patients who wish to see their records should be able to, however. A record would not be forced on someone who prefers to rely solely on what his physician chooses to tell him. (29) As the studies discussed earlier indicate, there is likely to be less patient anxiety, not more, where there is access. (30) Moreover, if there were exceptions to access only for psychiatric and terminally ill patients, the patient who is denied access would assume (perhaps inaccurately) that she falls into one of the exceptional categories but could only speculate about the actual content of the records.

It is also suggested that a patient who reads his own record will attempt self-medication. Some enlightened doctors have realized, however, that self-care for minor ailments should actually be encouraged. Drs. Vickery and Fries,

in their book Take Care of Yourself: A Consumer's Guide to Medical Care, suggest that, "As an enlightened medical consumer, you can save money and time, and provide for the best possible medical care for yourself and your family. You can learn how to treat many medical problems at home." (31) Patient access to records would probably lead to shorter, more efficient (and less costly) visits and to fewer visits per patient per year. (32) Vickery and Fries estimate that 70% of all visits to doctors are unnecessary. (33) Hidden behind the AMA's warning on patient self-treatment, in fact, may be the medical profession's gravest fear with regard to patient access to medical records: many patients would discover that they are overusing doctors.

NOTES (IMPORTANCE OF ACCESS)

- 1 The Report of the Privacy Protection Study Commission: "Record keeping in the medical-care relationship." Personal Privacy in an Information Society. Washington, D. C., Government Printing Office, 1977, pp. 277-317.
- 2 Medical Committee for Human Rights: Your Rights As A Hospital Patient. Cambridge, Ma., Greater Boston Chapter MCHR, 1975, pp. 21-22.
- 3 Privacy Commission report, note 1, supra.
- 4 Westin AF: "Primary health care records." Computers, Health Records, and Citizen Rights. United States Department of Commerce, National Bureau of Standards. Washington, D. C., Government Printing Office, 1976 (NBS monograph 157), p. 27.
- 5 United States Department of Health, Education, and Welfare: Medical Malpractice: Report of the Secretary's Commission on Medical Malpractice. Washington, D. C., Government Printing Office, 1973 (DHEW Publication No. (OS) 73-88), Appendix pp. 179-80.
- 6 McClain WE, ed.: "A Summary of Freedom of Information and Privacy Laws of the 50 States." Access Reports (April 1977), p. 2.
- 7 Medical Malpractice report, note 5, supra.
- 8 Privacy Commission report, note 1, supra, pp. 284-88.

9

Privacy Commission report, note 1, supra; Westin, note 4, supra; Westin AF: "Medical Records: Should Patients Have Access?" Hastings Center Report, Dec. 1977, pp. 23-8; Kaiser BL: "Patients' Rights of Access to Their Own Medical Records: The Need for New Law," Buffalo L. Rev., 24:317-30, 1975.

10

Annas GJ: "Hospital records." The Rights of Hospital Patients. New York, Avon Books, 1975, pp. 112-20.

11

Westin, note 9, supra; Annas, note 10, supra; Shenkin BD, Warren DC: "Giving the Patient his Medical Record: A Proposal to Improve the System." New Eng J. Med., Sept. 27, 1973, pp. 688-91.

12

"Patient Compliance: The Overlooked Aspect of Malpractice." Health Care Week, June 5, 1978.

13

Bouchard RE, Eddy WM, Jufo HM, et al: "The Patient and His Problem-Oriented Record." Burlington, Vt., University of Vermont Given Health Care Center.

14

Fischbach RC, Bayog AS, Needle A, et al: "Having Given the Patient His Medical Record: A Follow-Up on 'A Proposal to Improve the System'."

15

Eggers R: "I make my patients be their own doctors." Medical Economics. June 12, 1978, pp. 83-5.

16

See, for example, Millman M: "Keeping the patient uninformed and closing the ranks." The Unkindest Cut: Life in the Backrooms of Medicine. New York, William Morrow and Co., Inc., 1977, pp. 136-53.

17

Fischbach, note 14, supra.

18

Golodetz A, Ruess J, Milhous RC: "The Right to Know: Giving the Patient His Medical Record," 57 Arch Phys Med Rehabil, Feb. 1976, pp. 78-81.

19

Kaiser, note 9, supra; Annas, note 10, supra; Shenkin, note 11, supra.

20

AMA statement before the Privacy Protection Study Commission. June 10, 1976.

- 21 Westin, note 9, supra; Kaiser, note 9, supra; Annas, note 10, supra.
- 22 See Weed LL: Your Health Care and How to Manage It. Vermont, Essex Publishing Co., Inc., 1975, for an example of a sloppy record.
- 23 Annas, note 10, supra.
- 24 Annas, note 10, supra, "The Patient's rights advocate," pp. 209-16.
- 25 Annas, note 10, supra, pp. 209-16.
- 26 Westin, note 9, supra.
- 27 Kaiser, note 9, supra.
- 28 Medical Malpractice Commission report, note 5, supra, p. 75.
- 29 Kaiser, note 9, supra.
- 30 Bouchard, note 13, supra; Fischbach, note 12, supra.
- 31 Vickery DM, Fries JF; Take Care of Yourself: A Consumer's Guide to Medical Care. Mass., Addison-Wesley Publishing Co., 1976, p. 1.
- 32 Shenkin, note 11, supra.
- 33 Vickery, note 31, supra. Other authors have advocated self-treatment. See, for example, Sehnert KW, Eisenberg H: How To Be Your Own Doctor - Sometimes. New York: Grosset & Dunlap, 1975.
Sehnert KW, Nocerino JT: The Activated Patient: A Consumer-Oriented Program on Preventive Medicine and Self-Help Medicine. Washington, D. C., The Center for Continuing Health Education, Georgetown University. Nocerino JT, Pringle WB, Sehnert KW: Health Activation for Senior Citizens. Vienna, Virginia, Health Activation Network, 1977.
Medical Self-Care Magazine, Box 31549, San Francisco, Ca. 94131.

II. A STEP-BY-STEP GUIDE TO GETTING YOUR RECORDS

A. Overview of The Laws

1. State Laws

If you are not seeking records from a federal facility (see Section IV), your legal right to gain access to your medical record depends on what state you live in. The laws vary greatly from one state to the next in many respects. In many states, there is no legal right to access at all. State laws (statutes) that do grant access to patients are often limited in one or more of several ways. For example: (1) Coverage. The law may apply to hospital records but not doctors' records, or vice versa, or to public but not private hospitals. (2) Exclusions, such as for mental health records or parts of records or information which the provider believes will "harm" the patient. (3) Who has access. The statute may grant access to the patient herself or only to her attorney, physician, or other representative. (4) Form of access. Laws vary as to whether the patient can copy or only examine the record and as to whether the patient is entitled to the whole record or only a summary. (5) Prerequisites to access. Some statutes allow for access only in limited contexts, such as when the record is relevant to a lawsuit, when a court order to produce the record is obtained, when good cause is shown, or at the health care provider's discretion.

About a third of the states have statutes allowing for some sort of direct patient access, but half of these recognize only very limited rights. Another half dozen provide for access only by a patient's attorney or other representative. This leaves about half of the states with no statutes relevant to patient access at all.

2. Federal Hospitals

The Federal Privacy Act governs and allows patient access to medical records held by Public Health Service facilities, Veterans Administration hospitals, and military hospitals run by the Defense Department.

B. How to Get Your Records

Following are the steps we recommend you take if you want access to your medical records:

1. Know What Your Rights Are.

If the records are in a federal facility, consult the sec-

tion below on the Federal Privacy and Freedom of Information Acts. For state, local, and private facilities consult the state-by-state guide that follows in Section III to see whether or not your state has a statute granting access, just what type of access that statute allows, and any specified procedures or qualifications. If you do not reside in the state where your records are located, consult the law for both states. The law of the state of the provider will probably apply, but you should not hesitate also to cite the law of your state of residence if it has stronger patient access provisions.

Do not be discouraged before you start because your state does not have a statute granting access. Virtually all states that do not have statutes granting access also have no statutes denying it. In any case, health care providers are always free to consent to patient access, and some do even though they are not legally required to.

2. Contact the Hospital or Doctor.

Call the health care provider (in a hospital, the medical records department) whose records you wish to see and ask what procedures you should follow to obtain access. Some hospitals may have established procedures which are not specified in any state law. For example, you may be told to go in person to the hospital's medical records department or to put your request in writing first (which also may be required by state law).

If anything the doctor or hospital tells you is not consistent with the law in your state, you should immediately point it out, citing the statute. For this purpose, it would be advisable to have a copy of this book's description of your statute (if there is one) in front of you when you call.

For all telephone conversations, you should write down the date and time of the phone call, the name of the person you talked to, and what you were told. Such documentation may be valuable later.

3. Make A Written Request.

If you have not already been granted access as a result of your telephone call, you should make a written request which follows all the procedures specified in your state law and by the provider. In your letter, cite any relevant statute and refer to your telephone conversation where appropriate. Be as specific as possible, in making your request, as to which records you wish to see. If you wish to obtain copies of your record, specify which parts you wish copied and agree to pay reasonable costs of copying, if required.

Make carbon copies of all correspondence for your file,

as they may be useful in an appeal or litigation.

4. What To Do If Your Request Is Denied.

First, you should request that the provider put the denial in writing, give reasons for it, and tell you if there is any appeal procedure. Even if this is not done, however, you should proceed with the steps that follow.

Some hospitals (especially large ones) have established formalized grievance procedures and/or have "patient advocates" or "patient representatives" who are responsible for dealing with patient complaints. The Society of Patient Representatives, which is affiliated with the American Hospital Association, has about 1400 members at over 1000 institutions around the country. A list of all local chapters and representatives may be obtained by writing to the Society's central office in Chicago, (Society of Patient Representatives, American Hospital Association, 840 N. Lake Shore Drive, Chicago, Illinois). Contact the nearest chapter if the hospital has no patient representative. Unfortunately, it must be noted, even hospitals which have such a program often use it more for public relations than for patient advocacy.

Use whatever system the hospital has (if any) to appeal the denial. You should at least be able to get a written denial from the hospital administrator. If, after a reasonable time, there is no response, you should send a letter to the hospital administrator stating that you consider your request denied and will take further action to obtain your record.

5. Get Outside Help.

If your appeals are denied by the provider, you will want to consider other sources of assistance.

a. Patient's Rights Groups. Find out if there are any patients' rights advocates in your area and contact them for help. Patient advocates who are not affiliated with a hospital may be more outspoken in defending your rights. In Madison, Wisconsin, for example, several organizations have trained advocates who offer their assistance at no cost. (Contact Health Writers, Inc., 306 North Brooks St., 255-2255.) In Pittsburgh, Pennsylvania, contact the Patients' Rights Program, 231 Oakland Ave., Pittsburgh, Pa. 15213, 682-1738.

You may also want to try contacting groups in your area such as women's, minority, or gay health collectives or societies for the elderly such as the Gray Panthers. (You can get a list of local Gray Panther Groups from the national office at 3700 Chestnut St., Philadelphia, Pa. 19104.) The book Women's Health Care: Resources, Writings, and Bibliographies,

which can be purchased for \$4.00 (a discount is available if you are unemployed or do not have \$4) from Belita Cowan, Anshen Publishing, 556-2d St., Ann Arbor, Mich. 48103, has a directory of local women's and community groups. Cancer patients have formed a group called "Make the Day Count," which assists in obtaining medical records. Write to Box 303, Burlington, Iowa, for a list of local chapters.

If you do not know of any patients' rights groups in your area, you can contact a Public Interest Research Group (PIRG) or Citizen Action Group (CAG) in your state. (Write to the National PIRG Clearinghouse, 1329 E Street, N.W., Washington, D.C. 20004, for a list of these groups.) They may be willing to help you directly or can refer you to other consumer groups or lawyers. Try, also, contacting a local American Civil Liberties Union chapter (write to the ACLU's national office at 22 E. 40th St., New York, NY. for a list of local chapters) or a city, county, or state consumer affairs office.

b. A Friendly Physician. You may want to try having a doctor who will share the information with you make the request or you can ask that the record be sent to the doctor. Hospitals and physicians usually will release a record to a patient's doctor on request.

c. Contact A Lawyer. You may want to have a lawyer make the request on your behalf. In some states, lawyers but not patients are granted access by statute (either before or after a lawsuit is filed). If access is not granted, a threatened lawsuit (alleging either malpractice or just failure to disclose the records) probably would result in the records' release.

6. Sue The Provider

If you are willing and able to use a doctor or lawyer or threatened litigation, you will probably ultimately be successful in obtaining your records. However, if you are not or if you want to attempt to establish a judicial precedent for direct patient access in your state, you may want to consider pursuing a lawsuit, especially if a statute already provides for patient access. In the absence of such a statute, prospects for success in such a suit are not very great, and litigation is time-consuming. Thus, you may prefer to devote your time and energy to persuading your state legislature to pass a patients' rights bill (as groups are already doing in several states--see below) which provides for direct patient access.

C. How To Use Your Medical Records

1. Check your personal, family, and medical histories for accuracy and omissions. If you find mistakes, point them out

to your health care provider and make sure the original record is corrected. (See part D-5 below for discussion of correction of records.)

2. For any treatment you have had, you should look for four things:

a) What was the basis for the diagnosis?

b) What diagnostic tests, drugs, surgery or other treatment were administered?

c) What was the reasoning behind each of these? Were less expensive, more effective, or less dangerous alternatives seriously considered?

d) Is there evidence that the drugs or other therapy helped solve the problem? Did you have an adverse reaction to drugs or any other procedures?

3. Make a list of things in the record you do not understand and any questions you have. Consult your doctor or a nurse or a patient advocate about any things in the record that are unclear to you. You may also wish to consult a medical dictionary in your local library for an explanation of technical terms or abbreviations.

D. How To Get The Law Changed

1. The Privacy Commission Recommendations

The Privacy Protection Study Commission, created by the 1974 Federal Privacy Act, issued a report in July 1977 which included recommendations on patient access to medical records. The Commission recommended that both state and federal laws be adopted recognizing the right of "an individual who is the subject of a medical record maintained by a medical-care provider, or another responsible person designated by the individual" to have access to the record, "including an opportunity to see and copy it." (1) This recommendation is patterned after the provisions of the Privacy Act granting access by individuals to files about them held by federal agencies.

2. Pending Legislation

a. Federal Legislation. A federal bill (H.R.8283) based on the recommendation of the Privacy Commission was introduced in the House of Representatives in July of 1977 by Congressmen Koch and Goldwater. It would amend the Social Security Act to provide, among other things, for patient access to medical records maintained by medical-care institutions providing

services under the Medicare or Medicaid programs. This bill is now part of an omnibus bill being considered by Congress (Title V of H.R. 10076, introduced by Congressman Preyer). The Carter Administration also is preparing a set of recommendations on privacy-related issues, including medical records access, which will be transmitted to Congress later this year.

You should write to your Congressperson in support of this bill. We recommend that you include a statement urging that the bill be expanded to apply to doctors participating in Medicare and Medicaid as well as institutions.

b. State Legislation. Find out if there is any bill that would recognize the right of patient access to medical records pending in your state legislature. For this purpose, write to your state legislator or to the Secretary of the Senate or the Clerk of the House in the legislature at your state capital. These offices generally maintain an index of pending bills by number and by subject matter and will help you find any medical records access bills. If there is such a bill, write to your legislator and urge him or her to support it. If the bill is defeated, urge that it be re-introduced. If there is no bill pending, try to find someone to sponsor one.

For an example of how a patient-oriented model bill might be worded, see the recommendations of the Privacy Protection Study Commission. The recommendations are included in the Commission's report, Personal Privacy in an Information Society, which is available for \$5.00 from the Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402. Ask for Stock No. 052-003-00395-3. This book should also be available in local libraries.

In California, for example, a medical record access bill (No. 2470) was defeated in committee in April of 1978. The bill's sponsor, Assemblyman Howard L. Berman, hopes to re-introduce the bill next year. In Wisconsin, a hospital patient bill of rights (No. 418) which would guarantee the right of patient access to hospital records did not pass but may be re-introduced next year by its sponsor, David Clarenbach.

The Ohio legislature also is considering a hospital patient bill of rights (S.B. No. 202) which would recognize the right of patient access to hospital records. Bills providing for patient access were introduced in the Iowa legislature this year and should be re-introduced next year. (Sponsors were Norman Jesse, Julia Gentleman, and Minnette Doderer.) In Missouri, S.B. No. 882A would give patients in mental hospitals unrestricted access to their records and the right to challenge and correct any inaccurate data contained in such records.

If you learn of a bill on patient access pending in your

state legislature or are successful in getting one introduced, please send a copy to the Health Research Group, 2000 P Street, N.W., Washington, D.C. 20036.

3. State Agency Regulations

State agencies such as state health departments, hospital licensure agencies, and medical (physician) licensure boards have the power to promulgate rules allowing access. In Massachusetts, for instance, the state Board of Registration and Discipline in Medicine (which licenses physicians) is currently considering a proposal requiring doctors to allow patients access to their records. In Alabama, administrative regulations established by the State Board of Health govern questions of access to hospital records.

A patient's Bill of Rights for Pennsylvania was adopted by the state Department of Health in December of 1977. The bill includes a provision on patient access to hospital records (with an exception where access is specifically restricted by the attending physician for medical reasons). However, the Hospital Association of Pennsylvania has sued to enjoin its implementation. In New York, the Board of Regents has adopted professional standards (effective as of October 1, 1977) that uphold a patient's right of access to doctors' and other individual health care providers' records (with exceptions, see state-by-state guide).

Thus, you should write to agencies such as the state health department or the state medical licensure board to urge them to adopt medical record access regulations.

4. Posting Of Statute And Compliance By Providers

A law on patient access should include a clause requiring health care providers to post a statement of patients' rights. Even in states where access is permitted by law, it often is discouraged in practice. This tendency is encouraged by the fact that few patients know of the existing law or are able to challenge statements that access is not allowed. (2) A 1975 survey conducted by the Massachusetts Public Interest Research Group found that only 3 out of 28 hospitals examined complied with the access law. (3) In Virginia, a 1976 statute provides for access to hospital records while a patient is in the hospital. Yet a couple in Fairfax, Virginia was unable to see their baby daughter's records. The hospital insisted that patients were entitled to access to their records only after discharge, and, moreover, demanded an unreasonably high fee for copying the record.

5. Correction And Expungement of Records

A law on patient access should also include a provision

for patient correction of the medical record. The Privacy Commission recommended that procedures be established whereby, when a patient requests correction of a record, the medical provider would be required, within a reasonable time, either to make the correction or to inform the patient of its refusal to do so, the reason for refusal, and any procedures for appeal. If the request for correction were denied, moreover, the patient would be permitted to file a statement of disagreement which would become a part of the record.

The Missouri bill (S.B. No. 882A) on psychiatric records contains a provision which would give patients the right to a hearing to challenge the content of their records. A medical record with an incorrect or questionable psychiatric diagnosis can be especially damaging to the patient.

NOTES (A-STEP BY-STEP GUIDE TO GETTING YOUR RECORDS)

1

The Report of the Privacy Protection Study Commission: "Record keeping in the medical-care relationship." Personal Privacy in an Information Society. Washington, D. C., Government Printing Office, 1977, p. 298.

2

Soskis CA: "Patients' Access To Their Medical Records: The Current Situation." Health Law Project Library Bulletin, Nov. 1976.

3

Westin AF: Medical Records: Should the Patient Have Access? Hastings Center Report, Dec. 1977.

III. STATE-BY-STATE SURVEY OF LAWS

A. Guide To The Chart

The following chart presents an overview of the existing laws on patient access to medical records in the 50 states and the District of Columbia. More details about the content of each statute and judicial opinion are included in the state-by-state narrative after the chart. Following is an explanation of each of the columns in the chart:

1. Statutes

Any statutes on medical records access are noted. There is a blank for those states that have no relevant statute. Many states have statutes protecting the confidentiality of medical records. Such statutes typically provide that the content of the records will not be released to third parties (such as government agencies or insurance companies) without the patient's consent. Since these statutes do not deal with the issue of patient access, they will not be noted in the chart or discussed in the state-by-state survey of laws.

2. Case Law

Court decisions that deal with the issue of patient access to medical records are noted.

3. Records Covered

An X in the column headed Doctors' Records indicates that the law cited apply to doctors' (and often other individual health care providers') records. The same is true for the Hospital Records column.

4. Direct Patient Access

An X in the Right to Inspect column indicates that the law gives patients the right to inspect their own records. An X in the Right to Copy column indicates that the law gives patients the right to obtain copies of their records.

In some states, however, the right of direct patient access may be qualified by a statute that provides for access by "the patient, his physician, or attorney." Such statutes give a provider the option of releasing the records to a physician or lawyer rather than directly to the patient herself. These statutes also receive an X in this column.

5. Indirect Access Only

There are 2 types of indirect access: (a) A statute may

require a provider to release records to a third party, such as the patient's physician or attorney, but not directly to the patient. (b) A statute may require a provider to supply the patient or his representative with a summary of the record without requiring the provider to allow for actual inspection or copying of the record.

6. Special Provisions or Exceptions for Psychiatric or Mental Records

Some access statutes specifically exclude the disclosure of those parts of a record containing psychiatric information or of mental hospital records. Other statutes allow the provider to limit access or to furnish a summary instead of the record or to furnish information to a third party rather than to the patient.

7. Mental Health Statute

Some states have statutes specifically dealing with mental hospital patients' records. Typically, such a statute protects the confidentiality of the records, allowing for disclosure only with the consent of the patient or her guardian. Such a statute does not provide for direct patient access but does provide that information (not the record itself) regarding the patient's condition or medical record may be disclosed "upon proper inquiry" to appropriate third parties, such as family members, friends, a personal physician, or an attorney. An X in this column indicates that the state has a mental health statute. Only unique features of a particular state's statute are noted in the narrative that follows the chart.

8. Other Qualifications

An X in this column indicates that there is some other provision limiting access. For example, a patient may not be able to obtain a copy of a hospital record until after discharge. Or a doctor may be allowed to limit access if she feels that certain information would be harmful to a patient.

STATE	STATUTES	CASE LAW	RECORDS COVERED		DIRECT PATIENT ACCESS		INDIRECT ACCESS ONLY	SPECIAL PROVISION OR EXCEPTION FOR PSYCHIATRIC OR MENTAL RECORDS	MENTAL HEALTH STATUTE	OTHER QUALIFICATIONS
			DOCTORS' RECORDS	HOSPITAL RECORDS	RIGHT TO INSPECT	RIGHT TO COPY				
ALAB	Code of Alabama 22-50-62								X	
ALAS	Alaska Statutes 47-30-260								X	
ARIZ										
ARK										
CAL	California Evidence Code 1158		X	X			X			X
COL	Colorado Revised Statutes 25-1-801 to 803		X	X	X	X		X		X
CONN	Connecticut General Statutes Annotated 4-104			X	X	X				X
DEL										
DC	District of Columbia Code 21-562	Covington v. Harris, 419 F.2d 617 (1969) Emmett v. Eastern Dispensary and Casualty Hospital, 396 F.2d 931 (1967)							X	
FLA	Florida Statutes Annotated 458.16		X			X				
GEOR	Georgia Statutes Annotated 88-502.10								X	
HI	Hawaii Revised Statutes 622-57		X	X		X				X
IDAHO	Idaho Code 66-348								X	
ILL	Illinois Revised Statutes 51-71-73 and 73a	Cannell v. Medical and Surgical Clinic, S.C., 315 N.E.2d 278 (1974) Rabens v. Jackson Park Hospital Foundation, 351 N.E.2d 276 (1976)	X	X	X (hospital records)	X (doctors' records)	X	X		X

STATE	STATUTES	CASE LAW	RECORDS COVERED		DIRECT PATIENT ACCESS		INDIRECT ACCESS ONLY	SPECIAL PROVISION OR EXCEPTION FOR PSYCHIATRIC OR MENTAL RECORDS	MENTAL HEALTH STATUTE	OTHER QUALIFICATIONS
			DOCTORS' RECORDS	HOSPITAL RECORDS	RIGHT TO INSPECT	RIGHT TO COPY				
IND	Burns Indiana Statutes Annotated, Code Ed. 34-3-15.5-4			X	X ¹	X ¹				
IOWA										
KANS	Kansas Statutes Annotated 59-2931	<u>Pyramid Life Ins. Co. v. Gleason Hospital, Inc.</u> , 300 F.2d 858 (1961)							X	
KEN	Kentucky Revised Statutes 210.235								X	
LOU	Louisiana Revised Statutes 40:2013.3 and 40:2014.1			X			X		X	X
MAINE	Maine Revised Statutes Annotated 34-1-B								X	
MARY ²	Laws of Maryland 1975 ch. 521 adding to Annotated Code of Maryland, Article 46A - Insurance Code - Sec. 490c									
MASS	Annotated Laws of Massachusetts ch. 111-70 ch. 123-36	<u>Bane v. Superintendent of Boston State Hospital</u> , 216 N.E. 2d 111, cert. denied, 385 U.S. 842 (1966) <u>Doe v. Commissioner of Mental Health</u> , 362 N.E. 2d 920 (1977)		X	X	X		X	X	
MICH	Michigan Compiled Laws Annotated 14.800 (745)	<u>Caertner v. State</u> , 147 N.W. 2d 429 (1971)							X	
MINN	Chapter 380, Laws 1977; adds Section 144.335 to Minnesota Statutes Annotated		X	X		X				X

1. A statute provides only that hospital records should be "readily available" to the patient.
2. A statute provides only for patient access to medical information in insurance company files.

STATE	STATUTES	CASE LAW	RECORDS COVERED		DIRECT PATIENT ACCESS		INDIRECT ACCESS ONLY	SPECIAL PROVISION OR EXEMPTION FOR PSYCHIATRIC OR MENTAL RECORDS	MENTAL HEALTH STATUTE	OTHER QUALIFICATIONS
			DOCTORS' RECORDS	HOSPITAL RECORDS	RIGHT TO INSPECT	RIGHT TO COPY				
MS	Mississippi Code Annotated 41-9-65			X			X			X
MO										
MONT										
NEB		<u>Bishop Clarkson Memorial Hospital v. Reserve Life Insurance Co.</u> , 350 P.2d 1006 (1965)		X	X	X				X
NEV	S.B. 185 (1977); adding new sections to Chap. 629, Nevada Revised Statutes		X	X	X	X				
NH										
NJ	New Jersey Statutes Annotated 30:4-24.3 2A:82-42	<u>Bush v. Kallen</u> , 502 A.2d 142 (1973)		X	X				X	X
NM										
NY	McKinney's Consolidated Laws of New York, Sec. 15-13, Mental Hygiene Law; New York Official Compilation of Codes, Rules, and Regulations, 720.20(p) (1971); Rules of the New York State Board of Regents Relating to Definitions of Unprofessional Conduct (1977) 29.3(a)(7); 29.1(b)(13)	<u>Application of Weiss</u> , 147 N.Y.S.2d 455 (1965) <u>Hottkin v. Miller</u> , 379 F.Supp. 859, aff'd, 514 F.2d 125 (1974) <u>Palmer v. Durso</u> , 393 N.Y.S.2d 398 (1977)	X			X			X	X
NC	General Statutes of North Carolina 122-8.1								X	
ND										
OHIO	<u>Wallace v. University Hospitals of Cleveland</u> , 172 W.E.2d 459 (1961)			X						

STATE	STATUTES	CASE LAW	RECORDS COVERED		DIRECT PATIENT ACCESS		INDIRECT ACCESS ONLY	SPECIAL PROVISION OR EXCEPTION FOR PSYCHIATRIC OR MENTAL RECORDS	MENTAL HEALTH STATUTE	OTHER QUALIFICATIONS
			DOCTORS' RECORDS	HOSPITAL RECORDS	RIGHT TO INSPECT	RIGHT TO COPY				
OKLA	Section 3, ch. 44, O.S.L. (as amended, 1977)	<u>Pyramid Life Ins. Co. v. Masonic Hospital Ass'n</u> , 191 F. Supp. 51 (1961)	X	X	X	X		X		
OREG	Chap. 812, Laws 1977		X	X		X		X		X
PENN	Pennsylvania Statutes Annotated 50-4602								X	
RI										
SC										
SD										
TENN	Tennessee Code Annotated 53-1322 33-306			X			X		X	X
TEX	Revised Civil Statutes of Texas, Mental Health Code Art. 5547-37	<u>Morris v. Hoerster</u> , 348 S.W.2d 642 (1961) <u>Hutchins v. Texas Rehabilitation Commission</u> , 544 S.W. 2d 802 (1976)		X	X	(case law)			X	
UTAH	Utah Code Annotated 78-25-25 64-7-50		X	X			X		X	
VER										
VIRG	Sec. 8-277.1, Code of Virginia (as amended, 1977) Sec. 2.1-342, Code of Virginia (1976)		X	X		X		X		X
WASH										
WV										
WIS	Wisconsin Statutes Annotated 269.57(4) 908.03(em)(b)	<u>Fanshaw v. Medical Pro. Ass'n of Fort Wayne, Ind.</u> , 190 N.W.2d 155 (1971)	X	X			X			
WYO										

B. State By State Narrative

(States that have no access statutes are omitted.)

Alabama

A statute provides that mental health records are to be disclosed only on court order (Code of Alabama:22-50-62).

Alaska

A mental health confidentiality statute provides for disclosure of information concerning the current medical condition of the patient to the patient's immediate family (Alaska Statutes 47-30-260).

California

Medical records will be made available to a patient's attorney upon the written authorization of the patient prior to filing an action (Cal Evid Code 1158). This provision does not apply to the records of mental patients. (Cal Op Att'y Gen 151; Cal Welf & Inst'ns Code 5328.)

Colorado

A 1976 Colorado statute provides that every patient record, both in the custody of a hospital or related facility or institution and "in the custody of a chiropodist or podiatrist, chiropractor, dentist, doctor of medicine, doctor of osteopathy, nurse, optometrist, or physical therapist" shall be available for inspection to the patient or his designated representative at reasonable times and upon reasonable notice. A "patient record" does not include a "doctor's office notes" (undefined). Moreover, the statute specifically excludes "records pertaining to psychiatric or psychological problems or notes by a physician that in the opinion of a licensed physician who practices psychiatry and is an independent third party would have significant negative psychological impact upon the patient." However, a "summary of records pertaining to a patient's psychiatric or psychological problems may, upon written request and signed and dated authorization, be made available to the patient or his designated representative following termination of the treatment program." A patient is entitled to a copy of her records, including x-rays, upon "reasonable notice" in the case of individual health care providers, and following discharge in the case of hospital records. Such records must be furnished upon submission of written authorization-request, dated and signed by the patient, and upon payment of reasonable costs (Colorado Revised Statutes (1973), 25-1-801 to 803).

Connecticut

A statute gives the patient the right of access to his hospital records, but only after discharge, and makes no mention of doctors' records. "Each private hospital, public hospital society or corporation receiving state aid shall, upon the demand of any patient who has been treated in such hospital and after his discharge therefrom, permit such patient or his physician or authorized attorney to examine the hospital record, including the history, bedside notes, charts, pictures and plates kept in connection with the treatment of such patient, and permit copies of such history, bedside notes and charts to be made by such patient, his physician or authorized attorney" (Connecticut General Statutes Annotated (1969) 4-104).

District of Columbia

The medical record of a public hospital mental patient shall be made available upon the patient's written authorization to the patient's attorney or personal physician (District of Columbia Code, 21-562; Covington v. Harris, 419 F. 2d 617 (1969)).

A 1967 federal appeals court decision held that a deceased patient's son had a right of access to his father's hospital records without having to resort to legal proceedings (Emmett v. Eastern Dispensary and Casualty Hospital, 396 F. 2d (1967)).

Florida

A statute provides for access to doctors' records but makes no mention of hospital records. "Any doctor or other practitioner of any of the healing sciences making a physical or mental examination of, or administering treatment to any person, shall upon request of such person...furnish copies of all reports made of such examination or treatment" (Florida Statutes Annotated 458.16).

Georgia

A statute making state hospital records confidential provides that the records may be released to physicians, attorneys, and government agencies as designated by the patient (Georgia Statutes Annotated 88-502.10)

Hawaii

"If a patient of a health care provider...requests copies of his or her records, the copies shall, if available, be made available to the patient unless in the opinion of the health care provider it would be detrimental to the health of the patient to obtain the records." In such case, upon presentation of a proper authorization signed by the patient, "complete

and accurate copies of the records" shall be given to the patient's attorney within a reasonable time not to exceed 10 working days. Reasonable costs incurred by a health care provider in making copies of the medical record are to be borne by the requesting person (Hawaii Revised Statutes 622-57).

Idaho

A mental health confidentiality statute provides for the disclosure of information contained in the records to the patient's family, relatives, friends, lawyer, or physician (Idaho Code 66-348).

Illinois

A 1974 Illinois appellate court case held that the "fiducial qualities of the physician-patient relationship" require the disclosure of medical data to a patient or his agent on request (Cannell v. Medical and Surgical Clinic, S.C., 315 N.E. 2d 278 (1974)).

A 1976 statute provides for access to private and public hospital records after a patient's discharge. The hospital is to permit "the patient, his physician or authorized attorney to examine the hospital records, including but not limited to the history, bedside notes, charts, pictures and plates" and to permit copies of such records to be made by the patient or his physician or attorney. Records relating to psychiatric care or treatment are excluded and the statute does not apply to mental patients.

Another statute provides for the examination and copying of a physician's records by a patient's physician or authorized attorney, but not by the patient herself. The records include but are "not limited to those relating to the diagnosis, treatment, prognosis, history, charts, pictures and plates." Demand for access to records is to be made in writing and delivered to the physician. The demand is to be complied with within a reasonable time and the person requesting the records is to pay reasonable expenses of examination and copying. Records relating to psychiatric treatment and diagnosis are exempted from access "unless otherwise ordered by the court for good cause shown." To obtain psychiatric records, the patient should apply to the circuit court of the county in which the patient resides or the county in which the physician resides.

Records of a clinical psychologist are exempted from access unless the clinical psychologist consents or a court orders disclosure upon a showing of good cause (Illinois Revised Statutes, 51-71-73 and 73a; Rabens v. Jackson Park Hospital Foundation, 351 N.E. 2d 276 (1976)).

Indiana

A statute provides that hospital records should be readily available to authorized persons, including the patient and other persons with the patient's written authorization. There is no mention of physicians' records (Burns Indiana Statutes Annotated, Code Ed. 34-3-15.5-4).

Kansas

A statute making the medical records of a mentally ill person confidential contains an exemption allowing disclosure when the patient consents in writing. However, the head of the treatment facility, except an adult care home, may refuse to disclose portions if he or she states in writing that such disclosure would be injurious to the welfare of the patient. Otherwise, the records will be disclosed on court order or in proceedings under the statute on the request of an attorney (Kansas Statutes Annotated 59-2931).

A 1961 court decision denied an insurer an injunction to compel a hospital to permit it to inspect the records of insured patients, notwithstanding that the insurer had written authorization from the patients to inspect the records (Pyramid Life Ins. Co. v. Gleason Hospital, Inc., 360 P. 2d 858 (1961)).

Kentucky

A mental health confidentiality statute provides for the disclosure of information regarding the patient's medical condition to family and friends (Kentucky Revised Statutes 210.235).

Louisiana

A statute provides for the inspection of medical records of a patient in a hospital for the mentally ill administered by the Department of Health by the patient's attorney or near relative. A written request should be directed to the hospital superintendent (Louisiana Revised Statutes 40:2013.3).

Another statute provides only for limited access to records in a general hospital administered by the Department of Health and Human Resources. The superintendent is directed to furnish, on written request, a report to the doctor who refers a patient to the hospital. The report, available after discharge, should show the diagnosis, laboratory and x-ray findings, and treatment prescribed. Upon written request, the patient or her attorney is entitled to receive a full report on the patient. This is not the same as the whole record (40:2014.1).

Maine

A mental health confidentiality statute provides for the disclosure of information regarding a patient's condition to his spouse or next of kin (Maine Revised Statutes Annotated 34-1-B).

Maryland

The only statute relating to patient access to medical records involves those held by insurance companies. Medical files compiled by insurance companies under life or health policies are to be made available for inspection on demand by an applicant, claimant, or his agent. Information provided to the company by a physician will only be made available 5 years from the date of the medical exam unless the doctor consents in writing to earlier disclosure (Laws of Maryland 1975 ch. 521 adding to Annotated Code of Maryland, Article 48A - Insurance Code - Sec. 490c).

Massachusetts

A patient may have access to her records held by a hospital or clinic licensed by the Department of Public Health or supported in whole or part by the Commonwealth. The records may be inspected by the patient or her attorney upon delivery of the written authorization of the patient. A copy will be furnished upon request and payment of a reasonable fee. Mental hospital records are excluded. (Annotated laws of Massachusetts ch. 111 - 70).

A 1966 court decision held that the refusal to permit a patient at a mental hospital to examine and obtain copies of his record of involuntary admission and detention did not violate a constitutional provision making officers of the government accountable to the people (Bane v. Superintendent of Boston State Hospital, 216 N.E. 2d 111, cert. denied, 385 U.S. 842 (1966)).

Mental health records will be disclosed on court order or to the attorney of the patient if requested by the patient or her attorney (ch. 123 - 36; Doe v. Commissioner of Mental Health, 362 N.E. 2d 920 (1977)).

Michigan

Information in the record of a mental patient will be disclosed to the patient's attorney with the patient's consent (Michigan Compiled Laws Annotated 14.800 (748)).

A 1971 court decision interpreted a statute making medical records confidential (MCLA 600.2157) to imply that the right to confidentiality could be waived by the patient. The Supreme

Court of Michigan held that, upon proper showing, courts may take appropriate action to suppress portions of a mental patient's records as necessary adequately to protect the patient, but that otherwise a patient or his lawful representative should have access to all of the patient's hospital records." (Gaertner v. State, 187 N.W. 2d 429 (1971)).

Minnesota

A 1977 statute gives a patient the right of access to her medical records. "Upon request a provider shall supply to a patient complete and current information possessed by that provider concerning any diagnosis, treatment and prognosis of the patient in terms and language the patient can reasonably be expected to understand." Moreover, "upon a patient's written request, a provider at a reasonable cost to the patient shall furnish to the patient: (a) copies of the patient's health record, including but not limited to laboratory reports, x-rays, prescriptions, and other technical information used in assessing the patient's health condition; (b) the pertinent portion of the record relating to a specific condition, or (c) a summary of the record." However, if a provider "reasonably determines that the information is detrimental to the physical or mental health of the patient, or is likely to cause the patient to harm himself or another, he may withhold the information from the patient." In such a case, the information may be supplied to "an appropriate third party or to another provider" and that person may release the information to the patient (Chapter 380, Laws 1977; adds section 144.335 to Minnesota Statutes Annotated).

Mississippi

Hospital records are the property of the hospital, subject to "reasonable access to the information contained therein" upon a showing of "good cause" by the patient or his representative and upon the payment of a reasonable fee (Mississippi Code Annotated 41-9-65).

Nebraska

In a 1965 8th Circuit Court of Appeals decision, the court upheld the right of a hospitalization insurer to examine and copy the original hospital records of patient-policyholders who had consented to such inspection in connection with the processing of claims against the insurer. The court recognized that a patient had a property interest in his hospital record and that he or his authorized representative should have a right to inspect the record except "where the bona fide and good faith judgment of the patient's doctor dictates and he certifies under oath that the record not be released to the patient or authorized representative in the best interest of

the [patient's health]." (Bishop Clarkson Memorial Hospital v. Reserve Life Insurance Co., 350 F. 2d 1006 (1965)).

Nevada

A 1977 statute provides that "each provider of health care shall make the health care records of a patient available for physical inspection" by the patient or a representative with written authorization from the patient. The provider of health care shall also furnish a copy of the records when requested, subject to the payment of "costs of making the copy, not to exceed 60 cents per page for photocopies and a reasonable cost for copies of x-ray photographs and other health care records produced by similar processes" (S.B. 185; adding new sections to chap. 629, Nevada Revised Statutes).

New Jersey

A statute making the records of patients in state mental institutions confidential allows for disclosure of information as to a patient's current medical condition to any relative or friend or to a patient's personal physician or attorney if it appears that the information is "to be used directly or indirectly for the benefit of the patient" (New Jersey Statutes Annotated 30:4-24.3; Bush v. Kallen, 302 A. 2d 142 (1973)).

Another statute provides for the inspection of hospital records only in the context of a personal injury claim (2A: 82-42).

New York

A statute provides for the release of mental health records to a patient's attorney only in proceedings in which the patient's involuntary hospitalization is at issue (McKinney's Consolidated Laws of New York, Section 15-13, Mental Hygiene Law).

A 1955 New York Supreme Court decision held that a hospital cannot withhold a patient's record to prevent him from discovering the identity of the doctors who operated on or treated him (Application of Weiss, 147 N.Y.S. 2d 455 (1955)).

A statute now provides that a patient need be shown only enough of her hospital record to indicate which doctors attended her (New York Official Compilation of Codes, Rules, and Regulations 720.20 (p) (1971)).

A 1974 second circuit federal Court of Appeals decision held that a former mental patient was not deprived of property without due process of law when she was denied the right to inspect and copy her hospital records (Gottkin v. Miller, 379 F. Supp. 859, aff'd, 514 F. 2d 125 (1974)).

In a more recent case, a mental patient was granted access to his records, but only for the purpose of preparing an appeal from a decision upholding his certification as a mental incompetent. (Palmer v. Durso, 393 N.Y.S. 2d 898 (1977)).

Since October 1, 1977, professional-conduct standards adopted by the New York State Board of Regents uphold a patient's right of access to doctors' records. The standards require a licensed professional "to make available to a patient, or, upon a patient's request, to another licensed health practitioner consistent with that practitioner's authorized scope of practice, copies of reports, test records, evaluations or x-rays relating to the patient which are in the possession or under the control of the licensee." Reasonable fees may be charged for copies of records, "but prior payment for the professional services to which such records relate may not be required as a condition for making such records available." There is an exception, however. A practitioner may restrict patient access if, "in the reasonable exercise of his or her professional judgment, he or she believes release of such information would adversely affect the patient's health" (Rules of the New York State Board of Regents Relating to Definitions of Unprofessional Conduct (1977) 29.2 (a)(7)).

Complaints and requests for investigation regarding a health care professional's failure to provide access to records should be addressed to the State Education Department. The Board of Regents rules make it unprofessional conduct for a provider to fail "to respond within 30 days to written communications from the Education Department and to make available any relevant records with respect to an inquiry or complaint about the licensee's unprofessional conduct" (29.1 (b)(13).

North Carolina

A statute provides that state hospital records need be released only on court order (General Statutes of North Carolina 122-8.1).

Ohio

A court decision held that when a former patient requests to inspect her hospital record, the hospital may permit her to see as much of the record as it deems is in the beneficial interest of the patient. The patient may commence an action to require the furnishing of the entire record (Wallace v. University Hospital of Cleveland, 172 N.E. 2d 459 (1961)).

Oklahoma

A 1961 court case held that a patient has a property right in the information appearing or portrayed in his hospital record

and that he or someone authorized by him is entitled to inspect or copy the record without resort to litigation (Pyramid Life Insurance Co. v. Masonic Hospital Ass'n, 191 F. Supp. 51 (1961)).

Since 1977, patients have a statutory right to access. "Any person who is or has been a patient of a doctor, hospital or other medical institution shall be entitled to obtain access to the information contained in all his medical records upon request, and shall be furnished copies of all records pertaining to his or her care upon the tender of the expense of such copy or copies." Psychiatric records are excluded. (Section 3, ch. 44, O.S.L.) (as amended, 1977).

Oregon

A 1977 statute recognizes the "right of an individual to review his own medical records." Private practitioners and institutions are urged to adopt voluntary guidelines granting patient access. With regard to public agencies and publicly operated institutions, the statute provides that the record be released to the patient, upon written request, within a reasonable time not to exceed 60 days. The provider may supply a summary instead of the record itself. Psychiatric and psychological information may be withheld to prevent an adverse effect on treatment of the patient (Chapter 812, Laws 1977).

Pennsylvania

Records maintained by state mental institutions are open for inspection only by those persons designated by the director of the institution (Pennsylvania Statutes Annotated 50-4602).

Tennessee

Hospital records are the property of the hospital subject to a court order to produce. The hospital must provide "reasonable access to the information contained therein" upon a showing of "good cause" by the patient, his personal representative, or his attending medical personnel, and upon the payment of any reasonable charge for such services. (Tennessee Code Annotated 53-1322)

A mental health confidentiality statute provides for the disclosure of information regarding the patient's condition to family, relatives, or friends (33-306).

Texas

A mental health confidentiality statute provides for the release of information as to the patient's current condition to the patient's family, relatives, or friends (Revised Civil Statutes of Texas, Mental Health Code Art 5547-87).

A 1961 court decision held that a state hospital patient was entitled to inspect his medical records but that he must show that the evidence requested was relevant and material for the purpose of a suit or preparation for trial in a pending case (Morris v. Hoerster, 348 S.W. 2d 642 (1961)). A 1976 Texas Court of Appeals decision held that a former patient has a common law right to inspect his own records (Hutchins v. Texas Rehabilitation Commission, 544 S.W. 2d 802 (1976)).

Utah

A patient's attorney, but not the patient herself, is entitled to examine and obtain copies of the patient's record kept by a "physician and surgeon, dentist, osteopathic physician, registered nurse, psychologist, chiropractor, or licensed hospital." The attorney must present written authorization signed and acknowledged by the patient before a notary public and must pay for the copies (Utah Code Annotated 78-25-25).

A mental health confidentiality statute provides for disclosure of information contained in the record or information as to a patient's current medical condition to members of the patient's family or relatives or friends (64-7-50).

Virginia

A statute provides that "copies of hospital or physician's records or papers shall be furnished at a reasonable charge and within fifteen days of such request to the patient or his attorney upon such patient's or attorney's written request." If the treating physician includes in the patient's written record a statement that review by the patient of the record would be injurious to the patient, then the patient's attorney, not the patient, will receive the records. (Section 8-277.1, Code of Virginia) (as amended, 1977).

Another statute provides that a person may not personally review his own mental records when the subject person's treating physician has made a part of such person's record a written statement that in his opinion such review would be injurious to the person's mental health or well-being (Section 2.1-342, Code of Virginia) (1976).

Wisconsin

A statute allows for the inspection and copying of medical and hospital records by a person with written authorization and consent signed by a patient (Wisconsin Statutes Annotated 269.57 (4); Fanshaw v. Medical Pro. Ass'n. of Fort Wayne, Ind., 190 N.W. 2d 155 (1971)).

Another statute provides that hospital records are subject to subpoena "if upon a properly authorized request of an attorney, the hospital refuses, fails or neglects to supply within 2 business days a legible certified duplicate of its records at a minimum charge of \$5 per request. The rate shall be 10 cents per record per page and \$2 per x-ray copy" (908.03 (6m)(b)).

IV. OBTAINING MEDICAL RECORDS IN FEDERAL FACILITIES

A. Your Right To Access Under The Privacy Act

If the medical record you wish to obtain is maintained by a federal medical-care facility (such as a Veterans Administration hospital, Public Health Service facility, or military hospital), you have a right to access under the federal Privacy Act (5 U.S.C. §552a). The Privacy Act gives a person the right to inspect and copy his or her own medical records maintained by federal agencies and to contest inaccuracies in such records.

B. Variations In Procedures Among Agencies

The Act directs each agency to promulgate its own rules establishing access procedures. Thus, procedures vary among the Veterans Administration; Department of Health, Education and Welfare (which establishes procedures for Public Health Service facilities); and the Department of Defense (which governs procedures for military hospitals).

Furthermore, although a right to access is recognized, agencies are permitted to adopt special procedures where it is believed that direct access could be harmful to a person. (1) The Department of Health, Education, and Welfare has the most liberal procedures, providing for indirect access to records through a responsible individual designated by the patient. The third person is then free to reveal the contents of the record to the patient. (2) The Department of Defense provides that records that could be harmful to the mental or physical well-being of a patient be released to a physician of the patient's choice. The physician would then explain the contents of the records to the patient. (3) The Veterans Administration stipulates that records containing "sensitive medical information will be referred to a physician or other professional person with the necessary professional qualifications to properly interpret and communicate the information desired. This professional person may be selected by the individual provided the selectee meets VA professional standards or is licensed in the appropriate professional specialty." (VA Manual MP-1, Part II, Ch. 21, Sec. 6.d).

C. Making A Request

1. You can make a Privacy Act request in writing, in person, or by telephone. Some agencies may require, however, that a request be in writing. Call the hospital's medical records department to find out what procedures you should follow to obtain access to your records. If your records are stored at a place other than the hospital (as is the case of military hos-

pital records for former active duty members or records prepared for military personnel after retirement), the hospital should be able to tell you where to write to obtain copies of the records. Take notes on any telephone conversation to refresh your memory and provide documentation for any appeal.

2. If you are making a written request, include the following information:

(a) State that you are making a request under both the Freedom of Information Act (5 U.S.C. §522) and the Privacy Act (5 U.S.C. §552a). (Each act may give you access rights not available under the other.)

(b) Mark both the envelope and letter "attention: FOIA/Privacy Act request."

(c) Describe the document you wish to see as specifically as possible. (Include, for example, the date and place of treatment.)

(d) Give your full name, permanent address, and any earlier names under which the requested record may be filed.

(e) An agency may require you to supply additional information, such as previous addresses or your social security number. (If you do not wish to provide your social security number because it allows the agency to find other government records listed by social security number, you have a right to contest this requirement.)

(f) You may be required to provide a notarized signature. It is not necessary, in such a case, to go to a notary public. A federal statute (28 U.S.C. §1746) allows you to make an unsworn statement by use in writing of the following form:

"I declare (or certify, verify, or state) under penalty of perjury that the foregoing is true and correct.
Executed on (date).

(Signature)"

(g) State that you expect a response within 10 working days.

(h) Ask for information as to how to appeal any denial.

(i) Always make and file copies of all your correspondence so that you have documentation in case of appeal.

D. Time Requirements, Fees, Appeals

A request under the Privacy Act must be acknowledged within

10 business days of receipt of the request. The acknowledgment must say whether or not access will be granted. If it will be, your record must be produced within 30 business days.

Under the Privacy Act, you can be charged only the "actual cost" of copying a record. You should not be charged for searching, deleting exempted material, or preparing a record in a form suitable for inspection.

There is no provision for appeal of a denial under the Privacy Act, but some agencies may set up their own appeal procedures. Under the Freedom of Information Act, if your request goes unanswered for more than 10 working days or is denied, you can appeal to the head of the agency. An appeal must be answered within 20 working days.

E. Amendment Or Expungement Of Records

You have a right to demand an amendment of a record that is not "accurate, relevant, timely or complete." Each agency establishes its own procedures for handling requests for corrections. You should write to the agency or hospital stating what data you are challenging and what changes or deletions you are requesting. You may offer documentary evidence, if available, but you should include only so much as is necessary to show the validity of your request.

A request should be acknowledged within 10 business days of its receipt and should be acted on within 30 business days. A refusal letter must provide you with the appeal procedures. An appeal should be decided within 30 business days from the date the appeal is filed. If your appeal is denied, you have the right to file a "statement of disagreement" which will become a part of your record. The Privacy Act also provides for judicial review of refusals to amend a record as requested by the patient.

F. Freedom of Information Clearinghouse

If you are unable to get your records and you wish to pursue an appeal of a denial, you may want to write to the Freedom of Information Clearinghouse (P.O. Box 19367, Washington, D.C. 20036). The Clearinghouse, a Public Citizen group, will consider assisting you in your appeal effort, including litigation, if necessary.

HEALTH GUIDES FOR PUBLIC CITIZENS

These self-help books are available from the Public Citizen Health Research Group. Please send payment directly to the Health Research Group, Department 246, 2000 P Street, N.W., Suite 708, Washington, DC 20036. Price includes handling and fourth class mailing.

OFF DIABETES PILLS: A DIABETICS GUIDE TO LONGER LIFE. A paperback that warns against the use of blood sugar lowering pills by diabetics. It presents, instead, life saving alternatives to treat the disease. \$3.50

TAKING THE PAIN OUT OF FINDING A GOOD DENTIST. A how-to book for assessing the cost, ability and services of your local dentists. \$2.50

THROUGH THE MENTAL HEALTH MAZE: A CONSUMER'S GUIDE TO FINDING A PSYCHOTHERAPIST, INCLUDING A SAMPLE CONSUMER/THERAPIST CONTRACT. A book which advises consumers what questions to ask when looking for a therapist. It includes a list of drugs most often prescribed as well as different types of therapy. \$2.50

MEDICAL AND DENTAL X-RAYS: A CONSUMER'S GUIDE TO AVOIDING UNNECESSARY RADIATION EXPOSURE. A manual that outlines the abuse of x-ray examinations, how x-rays affect you, and how you can minimize your exposure. \$3.25

TRIMMING THE FAT OFF HEALTH CARE COSTS: A CONSUMER'S GUIDE TO TAKING OVER HEALTH PLANNING. A booklet that explains the process of health planning and how consumers can participate in local Health Services Administrations in order to reduce medical costs. \$2.75

A GUIDE FOR COMPILING....This series details step-by-step methods of producing local directories of DENTISTS (____ \$1.00) or PHYSICIANS' SERVICES (____ \$1.00). A must for local groups.

CHECK #	AMOUNT
NAME	
ADDRESS	
City	State Zip

PLEASE SEND THE BOOKS "CHECKED" ABOVE TO ME AT THIS ADDRESS.

Mr. PREYER. Our next witness is Mr. Leon Troyer. Mr. Troyer is a Federal employee who is testifying as a private citizen.

We thank you for being here today, Mr. Troyer. Your statement will be made a part of the record, and we recognize you at this time.

STATEMENT OF LEON TROYER, WOODBRIDGE, VA.

Mr. TROYER. I would like to say it is an honor to be here.

I want to start off by saying I agree with Dr. Wolfe in extending the legislation beyond just medical institutions down to the doctor level. This is where I am having my problem.

I am married and have two children, ages 11 and 14. I have been employed by the Federal Aviation Administration for the past 27 years, the last 7 of which have been in the headquarters office in Washington, D.C. This testimony is given on behalf of the individual and in no way involves the FAA.

In the past 19 years, I have moved my family eight times in keeping with the FAA's practice of mobility for career development. As a result of these moves, I have had considerable difficulty in maintaining medical and dental records for my family. The prime cause of this problem is that I am unable, as an individual, to obtain any medical records from the various doctors that I have employed. No doctor has ever allowed me to have any medical record for my family. They point out they are very willing to send them on to the next doctor. I don't have any problems with this practice if they would do it. You can't rely on it.

As an example, all of my records prior to 1968 are missing, and I have been unable to retrieve them.

Since I have lived in this area, I have had to employ 18 different doctors. Most of these are specialists that were recommended by my family doctor. Going back and trying to retrieve those records into one file has been physically impossible. Even my own doctor can't do this.

There is an additional problem that I have run into, and that is the ongoing feud between osteopaths and medical doctors. These two groups hardly speak to each other, let alone forward medical records. I have a feeling, of course, this is where my own medical records disappeared in the switching between osteopath and medical doctor.

The opposition which doctors have in allowing me to have my medical records seems to stem from three different areas. One, on who has ownership of the records. The doctors claim that since they assembled and did the work on the records that they have ownership. Of course, I, as an individual, feel that since I paid them to do this service for me, that the record belongs to me.

Doctors also feel that I could use these in legal claims against them. Of course, if necessary, I could get the records subpoenaed. The records can also be subpoenaed, for other legal action; so this is also an invalid argument.

The doctors claim that the language in the records could be detrimental to the person's mental health and don't want to divulge any information of this nature to them. I don't agree with that and feel anything in that record should be knowledgeable to me.

In today's world, when families are very transient, such as myself, it becomes increasingly important that these records follow us along. I have had to reconstruct several files. In fact, just recently, it cost me over \$500 just to get my wife's medical records reconstructed on one ailment.

An individual must be afforded the opportunity to have these records. The responsibility belongs to the individual.

That, gentlemen, is my statement.

Mr. PREYER. Thank you very much, Mr. Troyer. We appreciate your testifying. I hope most private citizens don't have your problem of moving eight times in 19 years and having 18 different doctors, but I am sure there are many people who, like you, work for agencies or large corporations which do require a number of transfers.

As I understand it, you have not yet been able to pull all of your medical records together?

Mr. TROYER. No, sir; I have never been able to get this accomplished. As I say, they are missing prior to 1968. I have gone back to doctors; in fact, one of these doctors is a personal friend of mine, and I was unable to get the record from him.

Mr. PREYER. So that you suggest if you, as an individual, would have the right to access to your entire records, you would keep the file yourself so that you would be sure that all of your records can be pulled together?

Mr. TROYER. Definitely. One of the problems I am having is in the area of my two children. My daughter has had considerable problems in recent years, and these records that we are now assembling will have a definite impact on her in later life, and she must, by all means, have those records. If I could assemble those records now, I would be sure of this.

Mr. PREYER. Thank you. We appreciate your bringing this problem and solution to our attention.

Mr. Kindness?

Mr. KINDNESS. Thank you, Mr. Chairman.

Thank you, Mr. Troyer.

Could you tell us a little bit about the kind of costs that you have incurred in assembling—you referred to your wife's medical records.

Mr. TROYER. Just recently, my wife came up with a thyroid condition. She explained to the family doctor she had had this problem before. Of course, he immediately wanted to check her records, and they were nonexistent. We went back to the prior doctors, and they either didn't have them or wouldn't take the time to look for them. I am not sure which.

At any rate, her current condition had to be assessed; so we sent her to the hospital and ran her through a complete bank of tests to get the information.

Mr. KINDNESS. You haven't encountered a situation where there was a charge for searching for the record or anything like this?

Mr. TROYER. No; I never have.

Mr. KINDNESS. I was just curious.

Thank you, sir.

Thank you, Mr. Chairman.

Mr. PREYER. Thank you very much, Mr. Troyer.

Our next witness is Barry S. Brown, prosecutor of Monroe County, Ind., representing the National District Attorneys Association. Since both of the bills before the subcommittee apply to State and local law enforcement agencies, in addition to the Federal agencies, we are especially interested in the views of the Nation's district attorneys.

Mr. Brown, it is good to have you with us today. Your statement will be made a part of the record, and you may proceed as you choose.

STATEMENT OF BARRY S. BROWN, PROSECUTOR OF MONROE COUNTY, IND., REPRESENTING THE NATIONAL DISTRICT ATTORNEYS ASSOCIATION

Mr. BROWN. Thank you, Mr. Chairman.

Monroe County is located in the southwestern portion of Indiana, 50 miles southwest of Indianapolis, Ind. It is the home of Indiana University, and is a good-size community for that part of the State.

I am pleased to be here, and it is a pleasure to represent the National District Attorneys Association with regard to what I view as very important legislation under review by your subcommittee in the area of privacy of medical information.

I would like to acknowledge at the outset to the members of the committee and you, Mr. Chairman, that I am not a professional lobbyist. I am not a draftsman. My area of expertise is in the interpretation of law and the application of law at the State level. My experience is not at the Federal level.

I would comment that my reading of both pieces of legislation, particularly H.R. 2979, indicates a well-conceived draft of this bill. I think there is good rapport between various sections of the bill. It is a credit to the staff and to the committee, itself.

I would apologize, also, for not being Mr. Dale Tooley. There was expectation, I think, on perhaps seeing him here today on behalf of the NDAA. However, I have had recent conversations with him concerning his testimony on the Senate side before the Committee on Governmental Affairs.

I would make it clear, also, that I favor the philosophy and the general policy behind the privacy legislation contained in H.R. 2979. I think there is a growing danger that if large-scaled transfers and dissemination of medical information, or all information becomes too common, we are going to lose our sense of what is private and move away from the privacy concepts of the fourth amendment.

I, also, frankly approve of the pursuit of Federal legislation as opposed to leaving the informational privacy activities to the uncertainty of State law. I think, certainly in an age of computer technology, it has been demonstrated that the increased data activity obliterates the significance of State boundaries, and it is important that a law such as the one that is before this subcommittee be homogeneous and as certain as possible. I think H.R. 2979 does accomplish that.

I did provide a statement in advance, and I would like to spend just a few minutes excerpting from that and respond to any questions you may have.

I begin talking on page 3 about the prosecutor's use of medical records. I tried to summarize those occasions and circumstances where at least in my own experience at the State level in Indiana, we became involved with medical records either in the prosecution of criminal acts or in the furtherance of other areas of investigation, such as in those circumstances where we confront medical records as frankly third-party intruders.

Most of those circumstances listed on pages 4 and 5 are ones that I had some personal contact with. Returning to page 4, I indicated that in those cases involving pleas of diminished intent or diminished capacity, specifically insanity, that I initially was somewhat concerned that perhaps this legislation would operate to prohibit the local prosecutor from having access to the past psychiatric history of the defendant raising that defense. However, I think there is language in H.R. 2979 which would permit intervening State law to supersede, and in most States—Indiana is no exception where a plaintiff raises issues regarding his medical condition—any privilege is deemed to have been waived, and I would presume for purposes of criminal prosecution cases involving the defense of diminished capacity or diminished intent, that prosecutors would not be prevented or prohibited by this legislation from having access to that very important information.

On page 5, at the bottom of the page, and on into page 6, I raise some questions, the same questions that Dale Tooley shared with me regarding the use of the verb "may" as the acting verb in describing the discretion permitting health care facilities to release information. My concern was that such language would signal the medical care facilities that they have a discretion which goes beyond what the bill originally anticipated or the framers of the legislation anticipated, and I am speaking from personal experience at the local level.

Most medical care facilities in this day and age, doctors and health care providers included, are very concerned about their civil exposure. There is a great deal of reluctance—and perhaps if Dr. Wolfe is still here, he would ratify that—by most practicing doctors to yield to the release of any kind of information without protection by court order or by other judicial decree. And, in my judgment, giving the medical care facilities this additional language may put them in the position of actually overruling or superseding the decisions and orders of the local courts.

I raise that as a concern. I am certain it is not an insoluble one, and that there is language that can be drafted to correct that.

At the bottom of page 6, I discuss the reasonable cause standard that was anticipated by some of the language in H.R. 2979, specifically section 141(a)(1). I really don't know, frankly, whether or not the reasonable cause standard was drafted to be equated with probable cause, or whether or not it is anticipated to be a lesser standard. Bob is nodding agreement, and I assume you would anticipate it would be a lesser standard than probable cause, but probably something more than mere suspicion.

Mr. GELMAN. That is the general attempt.

Mr. BROWN. There is some Federal authority for equating the reasonable cause standard with probable cause, and I don't have

that case cite with me and apologize for that, but I can provide that case to the subcommittee.

It might be, as a suggestion, that perhaps the definition section of the bill could include a clarification of that term so there is no confusion or ambiguity when interpreted at the local or State level, or the Federal level.

Moving to page 7, in discussing the challenge procedures contained in both bills, I raise some rather caustic concerns regarding the challenge procedure.

I suppose, as a prosecutor—as most prosecutors—I really fear equipping prospective defendants and all defendants with more tools than they already have to attempt to delay the criminal justice process. And I really am not familiar with the challenge and appeal process that has been proposed by H.R. 2979 and H.R. 3444 in terms of any analogous State-level criminal procedures.

There is nothing I can identify with at the State level, so perhaps my chagrin is really related to that lack of familiarity, but I do see some problems that I might have as a local prosecutor in Monroe County, State of Indiana.

First of all, if I could compare and distinguish between H.R. 3444 and H.R. 2979, in terms of the court of origin, or the court of location for the appeal process.

I believe H.R. 3444 in section 209 on page 37 specifies a local court or at least it anticipates the court that issued the subpoena will be the initial locus for the challenger's appeal.

In H.R. 2979, section 142, at page 29, the language provides for an appropriate U.S. District or State Court. Perhaps "appropriate" is a modifier that relates to whether or not it is a federally originated complaint, a complaint coming from the Federal system or the State system. If from a State system, I assume appropriate might mean in effect an individual must go to the State court. But it appears there is some discretion available to the individual.

It bothers me a little, because I think some prospective defendants or some individuals who are targets of a criminal investigation may seek the Federal court, often more lengthy, route as an effort to delay the investigation.

To that extent, H.R. 3444 makes it slightly clearer in my own mind. Perhaps section 142 in H.R. 2979 is more precise, but I have problems finding section 142 in 2979 workable.

The balancing standard that is anticipated in H.R. 2979, section 142, on page 29, is one that may cause some problems in judicial interpretation. I think the balancing standard is certainly an ideal that both bills more or less advance, although H.R. 2979 certainly focuses on that balancing standard. H.R. 3444, I think, retreats from the appellate court or the reviewing court adopting that standard in attempting to resolve the challenge by the individual. I do not challenge existence of that standard, but raise the questions as to whether or not that is really workable in terms of adopting a wide body of case law that is going to be understandable at the local level.

On page 8, I talk about the bill's enforcement sanctions producing a chilling effect. I guess being in the public sector, as most of you are and in the practical aspect of prosecuting defendants on a daily basis, I have some concerns, along with other law enforce-

ment officials, about my exposure to civil liability, and I am also concerned that there may be situations existing where the State or Government has operated in good faith in submitting an affidavit or information to a court as a basis for approval without authorization of the individual for access to records. This later may prove to be incorrect—not fraudulent, not surreptitious, but just incorrect—and that error committed in good faith, may give some opportunity for a defendant to seek a civil action at a later date without good cause and would expose the prosecutor or law enforcement officer or Government official defending that lawsuit, to unwarranted expense and anxiety.

Most State statutes provide—at least in Indiana, we have a good-faith clause—that gives us some—I hate to use the word—“immunity,” but some protection which statistically focuses on the intent as opposed to the conduct of the law enforcement officer.

On page 9, I talk about child abuse legislation and how I think H.R. 2979 and H.R. 3444, relate to that.

This is a very complicated area for me really to discuss. I am not certain I am the authority you need to hear with regard to child abuse legislation. I can speak of the projected effect of this legislation in Indiana. We have a recent law, which I attempted in my written statement to summarize in one paragraph, which essentially mandates the reporting of so-called suspected incidents of child abuse by all people who might be witnesses later on—doctors, physicians, lay people, school officials, and so forth. Medical care facilities are not exempted from that mandated reporting process.

I think H.R. 2979 makes an effort to reconcile that kind of potential conflict—at least in section 127. There is some effort made in H.R. 2979 to accommodate the existence of pre-existing State laws which require the disclosure of medical records. And I think certainly that could apply to child abuse, but, as I read section 127 in conjunction with section 102 on page 7, which seemingly does not anticipate the existence of pre-existing State laws, I am concerned that child abuse legislation at the State level may be supplanted by H.R. 2979. That may be a false fear, but I have some concerns in that area.

Referring to section 103 on page 8, which really equates the parents with the child in terms of the challenge procedures—I am concerned, as I point out on page 9, that this particular section may operate to protect the immediate disclosure of medical records affecting the life or health of a child where the parent is the prospective defendant or the suspect in a child abuse case. Again, I think there are provisions within H.R. 2979 that seek to accommodate that problem through application for delay of notice to the patient.

Again, I get back to the use of the permissive word “may.” In the face of all of the complex nature of the bill many hospital administrators may be reluctant to release the records, in the final analysis.

In my judgment, I think this bill should probably contain some language that speaks directly to the child abuse situation. Again, I am not a framer of legislative language, but I suggest that you may want to solicit a witness who could testify more specifically on that point: I am concerned in Indiana that the entire purpose of our

child abuse legislation might be thwarted or rendered inoperable by the existence of this bill, or may pose sufficient confusion so as to frustrate the full prosecution and enforcement of our own child abuse legislation.

I don't want to further beat a dead horse but section 127 of H.R. 2979 provides, that medical records disclosed by medicare facilities to governmental authority under this section, shall not be further disclosed if not otherwise prohibited by law where necessary to fulfill the purpose for which the record was obtained.

The purpose of the Indiana child abuse legislation is clearly to provide rehabilitative services not only for the abuser but also for the child involved. Prosecution and the law enforcement interests constitute a secondary purpose. My concern is that yes, records may be released or those records may be exempted under section 127 from notice, et cetera, and H.R. 2979 would not preempt local child abuse legislation, but when the rehabilitative function is satisfied, where does that leave law enforcement in terms of the prosecution phase. I see problems in the interpretation of the legislation by local prosecutors and by local courts.

I think my comments on page 10 are fairly self-explanatory. I get into the challenge procedure. I don't mean to suggest to the members of the subcommittee that I think expediency is the priority of law enforcement. I think we have to, and certainly the fourth amendment mandates that we defer to the rights and protections of individuals, but there are occasions when speed and all possible expediency are important to prevent greater injury and to apprehend a criminal suspect.

Finally, on page 11, I talk about need. I raise this question really because at the local level I am unaware of any problems that have existed at least in my own immediate jurisdiction, and, as president-elect of the State Prosecutors Association in Indiana, of any problems at the State level really indicating a need for subjecting law enforcement to those restrictions imposed in this legislation. At least in Indiana, I know of no situation where law enforcement officers have unlimited access to medical information without some prior intervention by a court, grand jury or other judicial process.

It is not possible in Monroe County for me to walk into the hospital, identify myself as a prosecuting attorney, and obtain medical records upon demand.

In my county, medical records are released to prosecutors only upon the authority of a court order. All court orders are either issued pursuant to an ex parte hearing or verified affidavit signed by the investigating officer or by the prosecuting attorney. In the cases of grand juries there have been a few instances where medical records have been subpoenaed, and obviously the grand jury process relies upon the inherent morality and high ethical standards within the grand jury system to protect against unwarranted intrusions.

I might respectfully propose, and, frankly, admitting I am not familiar at all with the resources that are available to your subcommittee, that perhaps some kind of needs study be done in the law enforcement sphere to determine whether or not there are widespread abuses. I am certain there are abuses, or you wouldn't have put this piece of legislation together, restricting access by law

enforcement officials, but is it necessary to embrace law enforcement officials in this sort of legislation to the extent anticipated?

I am not arguing against controls. I think there should be controls, but I am wondering if the controls already in existence, perhaps not standardized on a national level, are sufficient. They may not be, but in my experience they are in Indiana.

Thank you very much for listening.

Mr. ENGLISH [presiding]. Thank you, Mr. Brown.

Mr. Kindness?

Mr. KINDNESS. Thank you, Mr. Chairman.

Mr. Brown, I welcome you from the limestone country of Indiana, the birthplace of my wife, and things like that.

Mr. BROWN. Bloomington?

Mr. KINDNESS. Yes.

I really do appreciate the thoughtful presentation that you have made here today. It has given me some very, I think, cogent considerations to mull over. I don't really have any questions that occur to me, but I would like to ask this, as we go along in this process, if there are further questions that occur, I would like very much to have the opportunity to be in touch and confer with you on your reaction, because I think sometimes we operate here without sufficient benefit of the experience of people who have to deal with matters such as this day by day, and it is a classic case of where we might stomp around and trample too much grass down where it isn't necessary.

Mr. BROWN. I certainly would be available at any time.

Mr. KINDNESS. Thank you.

Thank you, Mr. Chairman.

Mr. ENGLISH. Thank you.

Counsel, do you have questions.

Mr. GELLMAN. Yes, I have a question or two.

The Department of Justice testified that many of their problems with the law enforcement sections in H.R. 2979 would be solved by exceptions from the challenge procedures for grand jury subpoenas. Do you agree with that?

Mr. BROWN. I am not familiar with the basis for the Justice Department complaints. I don't know that exempting grand jury subpoenas would solve all of the problems I have raised. If notice to the patient is to be a part of the process of gaining access to medical records, I am really not sure that is going to subvert the grand jury process, at least at the State level.

The grand jury system historically has been a highly trusted forum for inquiry into criminal conduct. It is perhaps abused in some situations, and I don't see the notice requirements as proposing any problem for the grand jury process except where the challenge procedure may delay the proceedings. If that can be cured, I don't see any problem.

If the grand jury is delayed, if it cannot conduct its inquiry because it must await the decision of a reviewing judge with regard to the challenge procedures, that could pose some serious problems at the State level.

Mr. GELLMAN. It has been suggested that we might be able to loosen up on some of the access restrictions for law enforcement agencies if at the same time we put in some kind of exclusionary

rule limiting the use of medical records that law enforcement people obtain.

For example, if you were doing an investigation of fraud and abuse in a medicare program and obtained the records for that purpose, you could only use them for that purpose. If you happen to find extraneous evidence in a record that a person had committed a crime—drug abuse, or something like that—you couldn't use that record against that person. Would you object to something like that?

Mr. BROWN. Let me respond to that on two levels, if I can. First: I think the exclusionary rule would operate in most cases, anyway, to limit the introduction of medical reports surreptitiously obtained.

Mr. GELLMAN. I am not necessarily talking about surreptitiously obtained.

Mr. BROWN. I understand. But I see the exclusionary rule operating, just as an aside here, as an effective means of restricting access to medical records as a practical matter by law enforcement agencies.

Second: If I can use the analogy of a law enforcement officer who has a search warrant, conducting a permissible search of the premises for contraband, as defined by the governing State law or the Federal statute, and while on those premises he not only finds the contraband described by the warrant, but he also discovers other evidence of criminal conduct which he believes may implicate the prospective defendant further, under existing law he is not precluded from using that in additional prosecutions.

I have some problems if your proposal is included within the present framework. For example, a government official is searching certain medical records during an authorized audit and uncovers evidence of abuse that involves individuals, and the identifiers were not removed from the medical records, my judgment inclination would be that if the government is there lawfully to begin with, if it was permissible to have access to those records initially, then it is unfortunate that a lawbreaker got caught, at least for the lawbreaker. I have some instinctive aversions to voluntarily limiting the capability of prosecuting when I see evidence of criminal conduct. I know that notice should be triggered at that point based on H.R. 2979.

Mr. GELLMAN. One of the problems is that with the growing role of the Federal Government and State governments in health care systems, financial auditors are demanding and getting access to more and more medical records of more and more individuals. We are theoretically not far from the day where financial auditors from HEW or State agencies could, in fact, review medical records of everybody, whether they are subject to medicare or not. That is a very hot issue these days. If you permit these kinds of collateral uses, you have a pretty simple method for permitting access. You give law enforcement the capability to review all medical records for any evidence of criminal wrongdoing of any type. That is going a bit further than anybody wants.

Mr. BROWN. I agree to a certain extent with that position. Is it possible to remove identifying social security numbers, names, and so forth, so as to insulate? I hate to be in a position of detecting

evidence of wrongdoing and being unable to react to it under the authority of my office.

If the Government uncovers collateral evidence of wrongdoing through a Federal audit, for example, and ongoing parallel investigation inclining the Government toward the suspect exists anyway, in the same sort of case for which the Government inadvertently uncovers the evidence, the accidental disclosure by the audit may, by your proposal, rob the Government of important evidence. The defendant may claim the exclusionary rule and say the Government came in contact with the incriminating evidence at this level. There is going to be a difficulty in the Government establishing at the outset that the investigation was already underway. What point in time did the Government have permissible right to that information? I would rather not know about it, and be able to act than to know about it and not be able to act.

Mr. GELLMAN. I have no more questions.

Mr. ENGLISH. Does staff have any questions?

Mr. MORR. I have no questions.

Mr. ENGLISH. OK, Mr. Brown. We deeply appreciate your testimony. It has been extremely helpful, and thanks again for being with us this morning.

[Mr. Brown's prepared statement follows:]

PREPARED STATEMENT OF BARRY S. BROWN, PROSECUTOR OF MONROE COUNTY,
IND., REPRESENTING THE NATIONAL DISTRICT ATTORNEYS ASSOCIATION

INTRODUCTION

Mr. Chairman and Members of the Subcommittee on Government

Information and Individual Rights:

Thank you for the opportunity to appear before you on behalf of the National District Attorneys Association to discuss the legislation introduced by Chairman Preyer relating to the privacy of medical records.

As you may know, the NDAA is the largest association of prosecuting officials in the United States, representing over 1,500 individual prosecutor offices and servicing 7,000 association members through a comprehensive array of training, consulting and informational activities.

While my views regarding the medical records privacy legislation under review by your committee may not be shared by every prosecutor, I believe that the general thrust of my testimony does represent a broad consensus of our nation's prosecutors and district attorneys.

My home jurisdiction, Monroe County, is located in southern Indiana, 50 miles southwest of Indianapolis, featuring a blend of rural and urban life-styles. A significant portion of the 100,000 plus citizens are directly or indirectly involved with Indiana University, which is a dominant influence affecting both the economy and the attitudes of the community.

We enjoy a relatively low incidence of violent crimes

against persons with the exception of a high rate of sex offenses. Recently, felony-level property crimes have escalated, particularly those involving theft offenses and burglary.

OVERVIEW

It is clear that the bills under review by this committee address a growing concern by a majority of Americans that our privacy is being eroded, and that we may ultimately be powerless to halt the indiscriminate and pervasive collection and dissemination of personal, medical information.

The omnipresent computer has revolutionized record-keeping, creating a system of information storage and disclosure that seems to defy even the most vigilant efforts to restrict access to these computerized dossiers which may contain intrusive, irrelevant, incomplete or inaccurate information.

I am also aware that this attractive reservoir of private medical data, whether computerized or not, lures both legitimate and illegitimate third-party interests to gain unwarranted access to personal medical records at the expense of individual rights.

Certainly the expose by Denver District Attorney, Dale Tooley, of a nationwide, multi-million dollar business involved in the trafficking of fraudulently-obtained private medical records is a chilling illustration of the abuse-potential attending unprotected access to medical records.

It is difficult to disagree with the general policy of non-disclosure of an individual's medical records reflected in the language of both bills. In my judgment, the broad interests

of law enforcement in protecting citizens against criminal acts and prosecuting wrongdoers are compatible with that policy.

Both bills appear to offer a similarly framed comprehensive solution to abuses, both existing and projected, which would adversely affect the rights and interests of American citizens. My concern, offered from the perspective of a full-time practitioner in the criminal justice system, is that the initial scope of this legislation, while grounded in meritorious policy considerations, may be so broad that it not only protects individuals from illegitimate and unwarranted access to their medical records, but unwittingly protects and offers sanctuary to law breakers by impeding the detection of and response to certain criminal acts.

My intention by this testimony is to comment on the anticipated impact of this legislation on the function and performance of the local prosecuting attorney. Reflecting on my experience as a county prosecutor, I hope to explore the vulnerabilities of the proposed law to intentional and calculated exploitation by wrongdoers.

The central objective of this legislation is best summed up in Section 2.(a)(6) of H.R.2979 in language which seeks to balance the legitimate interest in disclosing certain kinds of public information against a legitimate demand for individual privacy.

PROSECUTOR USE OF MEDICAL RECORDS

First, let me summarize those occasions and circumstances where medical records of suspects, prospective defendants, defendants, and other parties are necessary in the furtherance of the investigation

and/or prosecution of criminal acts. By this list I am not suggesting that these areas of law enforcement inquiry are frustrated by the presence of this legislation:

1. Rape Cases.

Knowledge of the blood-type of a suspect can assist in identifying the assailant, through a chemical analysis of semen deposits. Additionally, information revealing physical peculiarities, abnormalities or unexposed disfigurement can further aid in suspect identification where a victim has observed a suspect so afflicted. This information is commonly recorded on routine personal medical data.

2. Welfare or Medicaid Fraud.

Obviously, the grist of any prosecution for fraudulent representation of a need for government provided medical assistance are the actual medical records pertaining to the requested public assistance.

3. Child Abuse.

I include this category as a circumstance for seeking medical records in a criminal investigation in view of the provisions contained in Sec. 103 in H.R.2979 conveying the right of challenge to a parent or guardian of a minor. Where the parent or guardian is a suspect in a child abuse case, the child's right to challenge third party access would merge with that of the parent.

4. Cases Involving Pleas of Insanity

The psychiatric history of a defendant interposing

the defense of non-responsibility for the prohibited conduct by reason of mental disease or defect is critical in scrutinizing the validity of that defense.

5. Vehicular Homicide Involving Intoxication.

Blood samples are routinely drawn and tested incident to emergency room treatment. The blood alcohol content under most applicable state law is a requisite element of proof.

6. Raising Defense of Self-Defense.

Where a defendant in a battery or homicide case alleges the use of force for self-protection and where injury to the defendant results, then analysis of the location and characteristics of his injuries are key in testing the legitimacy of the claim.

7. Unwilling Victims.

In certain isolated cases, injured victims may be unwilling to cooperate with law enforcement officials in the conduct of an investigation even though the case requires prosecutorial action. Medical information relating to the victim's injuries incident to the relevant offense is essential to the furtherance of the case.

DISCRETION BY MEDICAL FACILITY TO DISCLOSE

Sections 121 through Sections 131 of H.R.2979, inclusive, only provide that the medical care facility "may" presumably at its discretion, disclose the requested medical record maintained about an individual, notwithstanding total adherence to the

, required procedure for access by the petitioning agency.

In my experience with hospitals and other medical care facilities, there exists an inherent reluctance to release records even in the presence of an abundance of lawful authority. In our highly litigious society, the medical profession at all levels is highly exposure-conscious, and in my judgment, the presence of this permissive or discretionary language in the proposed law would tend to intimidate some hospital administrators into imposing restrictions beyond those anticipated by H.R.2979.

Arguably, the use of the verb, "may," in the context of each of those relevant sections, would confer power exceeding that of the local court upon the medical facility, indeed, the power to "reverse" the ruling of the Court or subpoena of the grand jury.

If Congress is making the effort to draw the line between protection of an individual's medical records and the legitimate needs of law enforcement, then it should make that judgment now, rather than permitting a medical facility or a judge to draw different, arbitrary and highly subjective judgments. It is unrealistic to expect law enforcement officials to embrace legislation which establishes procedural hoops for officials to jump through and then once those procedures are followed, for the officials not to be entitled to the medical records. H.R.3444 is far superior to H.R.2979 in its provisions regarding access by law enforcement officials to medical records.

"REASONABLE CAUSE" STANDARD EXCESSIVE

The imposition of a "reasonable cause," "reason to believe," or "probable cause" standard necessary as a basis for the

issuance of a grand jury summons or subpoena, anticipates a standard that exceeds that required for the commencement of an investigation of other crimes where medical records are not involved.

Not all prosecutors are equipped with subpoena power absent the seating of a grand jury. Section 141(a)(1) of H.R.2979 would not only be mechanically awkward to implement, but would limit the investigative powers assigned to grand juries by most state statutes.

I am personally unaware of documented or reported abuse by the state grand jury system in obtaining individual medical records pursuant to a criminal inquiry which would justify supplanting the existing standard with one requiring a higher quantum of proof.

CHALLENGE PROCEDURE - A POTENTIAL TOOL FOR ILLEGITIMATE DELAY

Delay in the criminal process frequently operates to the advantage of the accused and the detriment of the prosecuting authority. In most cases the successful manipulators of the system are those defendants who are recidivists, skilled at exploiting constitutional safeguards to their advantage.

At the time of challenge by an affected individual, both bills appear to place the burden of establishing the legitimacy of the law enforcement inquiry upon the government. My initial reaction is that that burden should be located with the movant, who, in the language of both proposals, is the challenger.

The enforcement time constraints drafted in the law will operate to limit but not to thwart frivolous challenges inspired

by suspects exhausting their remedies in an effort to conceal or delay disclosure of medical information which may be incriminating.

Predictably, those with the most to lose will mount the stiffest opposition to disclosure of their medical records. I foresee the commitment of additional manpower and resources to respond to challengers fully implementing the challenge process.

Additionally, the two-pronged judicial standard defined in Section 142(d)(1), H.R.2979, requiring both a finding of legitimacy and relevance in the government's pursuit of the petitioned records coupled with the application of a balancing test involving an individual's privacy interest and governmental need, permits wide discretion in reviewing challenges, without clear statutory guidelines. That latitude in discretion will surely spawn a body of case authority which will defy uniformity and deny to law enforcement officials a clear, workable standard to apply in seeking legitimate medical information.

ENFORCEMENT AND SANCTIONS MAY PRODUCE CHILLING EFFECT

Absent the availability of a "good faith" absolute defense to liability for law enforcement officials who sincerely believe that they are operating in compliance with the law in seeking disclosure of medical records, many prosecutors and their deputies may hesitate to seek access under either bill unless they are armed with absolute verification of all allegations contained in their supporting affidavits, testimony or written certifications.

Most states, and indeed, the federal government, protect prosecuting officials from civil or criminal exposure when they have operated in good faith, notwithstanding the eventual disrepute of information originally believed to be accurate at the time asserted.

I know of instances where information supplied by informants and other third party witnesses is alleged as a basis for probable cause in the petition of a court order. Occasionally, that information or part of that information is later determined to be inaccurate or incomplete, through no intentional design by the affiant/law enforcement officer.

Under H.R.2979, proof of that error would expose all parties involved in the preparation of affidavit, certification or other supporting pleadings to civil, possibly criminal, liability.

CHILD ABUSE LEGISLATION INOPERABLE

Many states, including Indiana, have enacted child abuse legislation mandating the reporting of "suspected" child abuse by all potential witnesses and establishing misdemeanor criminal penalties for failure to disclose. Medical care facilities, along with private physicians and school systems, are included agencies within the provisions establishing the reporting duty.

Section 103 of H.R.2979 inserts the parent or guardian of an individual who is a minor as the "executor" of all rights otherwise available to affected individuals under the proposed law.

In those abuse cases where the suspect is also the parent or guardian of the child/victim, H.R.2979 may successfully operate to unwittingly protect the immediate disclosure of medical records/evidence relevant not only to the issue of probable cause for arrest but also to the life or health threatening issue of removing the child from the abusive environment.

IDENTIFICATION OF OFFENDER IMPEDED

While designed to offer protection and assurances of privacy for potential "victims" of illegitimate use of their medical records, under certain circumstances the erection of the procedural safeguards imposed by this legislation may actually frustrate the ultimate identification of lawbreakers.

Many of the exceptions to the general rule of non-disclosure of medical records, enumerated in Part C. of H.R.2979 and provided in Title II of H.R.3444, would permit release of records for conventional law enforcement activities, but with accompanying procedures which would effectively reduce the response time from the report of a crime to the identification of a suspect.

In my judgment, neither of these bills is designed to accomodate exigent or emergency situations demanding immediate access to a suspect's medical records for purposes of identification and subsequent apprehension. The unfortunate result may be the flight of a prospective defendant.

The condition precedent requiring the service of fourteen days prior notice to the target individual/suspect, with the availability of a state or federal court forum in which to challenge that release by the individual, could obviously further delay the receipt of the records, even if the law enforcement official is successful in establishing a lawful basis for their disclosure.

Section 129 of H.R.2979 does appear to offer some deference to expediency where the identification or location of a suspect is required in a legitimate law enforcement inquiry. However, when read in conjunction with Section 131 of the same bill

there may be an irresistible tendency by medical facility administrators to insist upon court sanctioned orders, required by Section 131, instead of mere "certification" thereby triggering the notice and challenge mechanisms structured in Part D of the bill.

THE QUESTION OF NEED

I raise the ultimate question. Is there a demonstrable need to restrict law enforcement access to medical records pursuant to legitimate inquiry beyond those safeguards already in existence?

In my experience, disclosure of private medical records is successfully screened, at least in our jurisdiction, through the formality of judicial review which attends the release of any medical information absent the individual's consent.

Fishing expeditions or otherwise unwarranted intrusions by law enforcement officials into private medical records is not legal under any circumstance in any jurisdiction. Moreover, while the informal, surreptitious disclosure of confidential medical records to law enforcement entities probably does and has occurred, in my judgment those situations illustrate the isolated exception, not the rule.

Those abuses connected with the illicit trafficking in stolen medical records and in the misuse of personal medical data by employers, credit reporting agencies, insurance providers, government agencies and others, do not appear to involve the routine investigative functions of our nation's law enforcement officials.

In short, law enforcement may have been unfairly identified along with the obvious abusers as an existing or potential third-

party transgressors in the business of violating the privacy of private medical records.

CONCLUSION

I anticipate that some of the questions raised in my remarks may be answered or the conflicts reconciled by a closer reading of both bills. I admit that certain of my fears might be allayed through a more skilled interpretation of the various qualifying and modifying provisions of both bills.

Yet I continue to harbor the haunting concern that the delicate balance so boldly proposed in the stated findings and purposes of H.R.2979 may be unfairly balanced against the interests of legitimate law enforcement inquiry under the scheme proposed by this legislation, further sacrificing the effectiveness of an already well-honed law enforcement capability.

Mr. ENGLISH. The last witness that we have today is Dr. Adele Hofmann, from the American Academy of Pediatrics. The issue of children's rights is one of the most difficult presented by the medical privacy legislation, and we are grateful for your advice.

Dr. Hofmann?

STATEMENT OF DR. ADELE HOFMANN, AMERICAN ACADEMY OF PEDIATRICS

Dr. HOFMANN. Thank you for the opportunity of appearing today.

Let me just state that the academy represents 20,000 board-certified pediatricians and has taken a major role in advocacy for children and adolescents. If I might make a distinction between children and adolescents, because there are major developmental differences, the dependency of a child on his parents is foregone, and the beginning and growing independence of an adolescent and the ability to represent themselves in health care and have special interests is a rather different matter.

I would urge the committee to conjure to their mind when I say the word "child," what it is that you think of? This is a small individual who is indeed dependent. Adolescents are somewhere between an adult and a child in their capacity to represent themselves.

The academy recognizes specifically both the semantic and the developmental difference and has a different division for adolescents in terms of recognizing it as a special group in pediatrics which now extends not just from infancy into childhood but to young adulthood and early twenties.

By way of background as to the representations of the academy in the whole issue of children and adolescents, I am going to just make a few remarks specifically from my written testimony. I am not going to read it in its entirety, but rather, for brevity, review those issues which I think are of particular concern and relevance to privacy of children and adolescents.

There are perhaps three particular dilemmas: (1) The longevity of a minor's record; (2) the possible conflict between parental and minor's interest; and (3) the need to insure that the exercise of health record rights privacy parallels minors' consents.

We also would like to take this opportunity to encourage legislation to be innovative in moving away from an either/or position for the adolescent, in particular; that is, either the minor or the parent, and to incorporate provisions consonant with human development in a kind of guided, collaborative, shared approach.

We find considerable difficulties with laws which take an either/or approach when we are dealing with the family unit and want to do both.

Let me explain the point I raised in more detail. First, health data for the child has a potential span in effect of 75 years or more. In addition, infinite data is collected about the health of the child with little regard for its future impact and implications. Numerous conjectures about a health problem may be recorded in establishing diagnoses; that is, it is quite possible to have a diagnostic entry of slow development, of early learning difficulties or epileptic seizures. All of these conditions may either represent transient or

long-term disability. If transient, the documentation may remain unchanged indefinitely to the detriment of the child.

I cite two specific examples. The first of a 10-year old boy diagnosed on the record in conjunction with another condition as having a functional heart murmur. That is insignificant by medical standards and is an event which occurs in approximately 40 percent of all children and adolescents at sometime or other. This individual was denied health insurance as an adult based on the history of a heart murmur.

A similar event befell a young woman who had a transient emotional adjustment problem and brief hospitalization at age 15. I think you are aware that many adolescents do have such problems. They are transient, do not have a poor psychiatric prognosis in any way, shape, or form.

I recognize this problem of the longevity of a child's record isn't substantively addressed in this legislation, but I point to it in underscoring the significant difference between privacy for children and that for adults.

Other factors for your consideration in this general vein are that children and adolescents do not know there even is a dossier about them if they have not participated in the exercise of privacy.

One may be 20 to 25, find an issue that has to do with early childhood health and not even know that it exists and be significantly disenfranchised from proper pursuits of identifying where the record is, what is in the record, if one does not have knowledge.

Parents are captive to traditional process on two counts. First, they seek the best for their children here and now and truly are unable to discriminate about information released as might an adult for himself. Contemplate your own child being in a hospital severely mentally or physically ill, and that you are asked information that you consider an invasion of your privacy, but you are not able to preserve this, or data about the child, himself, if you think that is going to help that youngster. Parents really, in their concern for the child, are unable to discriminate privacy issues.

A parent is captive to agreeing to reveal any information to anyone at any time if they believe the failure to do so would place their child in increased jeopardy to even the slightest degree. The situation that was mentioned by the previous witness in a child abuse situation, where the parent would withhold information that might be critical to the child's health in relation to their own culpability in relation to neglect.

Second, the major repository of the health data outside the medical record, itself, is in the insurance industry. Recognizing this, an adult individual is free to determine whether he shall seek recourse to third-party payment or not. The parent is in more of a bind, a conflict of interest, if you will. He perchance may recognize the potential labeling effect of diagnoses submitted to third parties but be in conflict in viewing economic issues as preeminent.

Thus, children must be involved in learning about, understanding and participating in their health record privacy just as soon as they are sufficiently mature. We deem such maturity to initiate or begin at about age 12, at which time abstract thought begins to emerge and develop.

The second major point is that according to both Federal and State law a number of adolescents are accorded permission to consent to various health care services. In part, this responds to pragmatic need and the view that a person's health has high priority, and the academy would hold that health has the highest priority, and in part to the recognition that the age of majority is an insufficient criterion to measure maturity and that a goodly number of minor young people have achieved developmental emancipation and can give an effective consent.

While consent addresses access to health care and the establishment of a patient/doctor contract, if you will, it also goes hand in hand with confidentiality, and indeed confidentiality is the core issue. The repository of health record rights in parents over medical care to which the minor, himself, consented and assumes is accompanied by confidentiality, is an obvious breach of that confidentiality. Health record privacy must parallel minor's consent permission in insuring that privacy is maintained throughout the health care transaction.

Last, I would like to speak to human development in the adolescent years. This is a unique time in the life cycle when emotional emancipation and independence emerge in preparation for adult autonomy. Critical to this process and the capacity to make mature judgments is the arrival of abstract thought or the process by which we can take current circumstances into consideration, make some reasonable estimate of future implications and consequences and take rational action out of this future vision. It is critical that we prepare our young as effectively as we can to take on adult autonomy. The law in general has failed to support and encourage this gradual process in being an either/or situation I spoke to a few minutes before—either the minor, or the parents, or at majority.

We would like to encourage legislation to take a landmark step in providing for a graduated responsiveness to adolescent maturation in affording an interim time of parent-child collaboration in the exercise of privacy rights. This not only prepares a minor in a guided fashion to assume such rights and effectively exercise them when fully mature, but promotes parent-adolescent communication and collaboration, a scarce commodity today. There is existent precedent for such a duality: (1) In existing DHEW regulations pursuant to drug and alcohol abuse records under the Federal Privacy Act, and (2) in the recommendations of the Commission for the Protection of Human Subjects of Biomedical Research.

In children it is recommended that children of 7 years or more assent, and parents give permission. The academy did offer testimony to those regulations that we would recommend that the adolescent consent, which is something more than assent. These are niceties, and I don't mean to get into the semantics except to point out that there are people beginning to look at the kind of duality that we need to introduce into adolescents and their parents in health care.

These issues are all explored in more detail in our written statement, and I have only outlined them, and I and the academy appreciate very much the opportunities to appear before you today in relation to the health privacy records and rights of children and adolescents, and I would be welcome to entertain questions at this point in time.

[Dr. Hofmann's prepared statement follows:]

American Academy of Pediatrics



Testimony

before the

Government Operations Committee
Subcommittee on Government Information and Individual Rights

Federal Privacy of Medical Records Act
H.R. 2979

Presented by

Adele D. Hofmann, M.D., F.A.A.P.

September 17, 1979

Division of Government Liaison
1800 North Kent Street
Arlington, Virginia 22209
703-525-9560

Mr. Chairman, I am Adele D. Hofmann, M.D. I am a board-certified pediatrician, Associate Professor of Pediatrics at New York University School of Medicine, and director of the Adolescent Medical Unit at Bellevue Hospital. I also serve on the Board of Directors of the National Commission on Confidentiality in Health Records and am currently chairperson of the American Academy of Pediatrics' Section on Adolescent Health. I have been a student of the issue of privacy, consent and confidentiality in minors' health care for many years. I am here today representing not only the American Academy of Pediatrics but also this nation's children and adolescents--a constituency with little voice in the legislative process but one having special and significant need with regard to the confidentiality and consent to release of their medical records. Children and adolescents have just as vital an interest in the protection of their privacy as do adults, but they are usually unaware of the importance or implications of those rights.

The Academy of Pediatrics considers it essential to insure that the special interests of children and adolescents receive deserved attention in any confidentiality of medical records legislation. We respectfully urge you to avoid the all-too-common but ill-founded presumption that any legislation addressing the privacy rights of adults is modifiable for minors simply by providing that parents exercise those rights on behalf of their children. We would caution that recent expansions of minors' rights and the mature minor doctrine, as well as the sometimes disparate interests of parents and young children call for specific legislative provisions to protect the interests of children and adolescents.

Before I outline the Academy's specific recommendations as to how we might address these problems, let me tell you something of the philosophy underlying those recommendations. That philosophy derives from the precarious balance which we attempt to strike between the rights of maturing children and adolescents and the desirability of avoiding intra-family polarization as that maturation process progresses. This necessitates seeing parents and minors as two distinct entities and recognizing the autonomy of those minors at an appropriate age and stage of development. This is admittedly no easy task, but we need not exacerbate the problem through incomplete consideration of privacy, confidentiality and consent issues.

The Academy strongly believes that any legislation touching on these issues must take a developmental approach, recognizing the expanding capacity of minors to determine their own affairs. The normal developmental process finds adolescents emotionally distancing and separating themselves from parents in the formulation of identity and acquisition of autonomy. They are uniquely dual in being members of the family unit, while at the same time beginning to separate themselves from that unit. This is an essential element in the growth process if the young person is eventually to function as an independent adult. Initiating independence in the health care setting is desirable from this developmental perspective as this can be supervised in a graduating and supportive manner by a concerned professional who is external to the distancing process.

Any legislation dealing with confidentiality of medical records must recognize that adolescents are increasingly competent in giving an informed consent--for either health care or the release of their records--and assuming responsibility for their own behavior by virtue of cognitive maturation and the arrival of abstract thought. Many states already have legal permissions for minors' consent to treatment of venereal disease, drug abuse and other conditions. When we speak of informed consent, we refer to the patients' having sufficient knowledge about the benefits and risks involved and sufficient intellectual competence to make rational judgments as to which course among the alternatives would be in his or her own best interest.

You can see, Mr. Chairman, that when the Academy recommends recognition of minors' rights in legislation dealing with confidentiality and consent to release of medical records, we do not propose to alienate the adolescent from his or her family. Any individual faced with an important decision is optimally benefitted by the loving counsel and caring support of a family member. This is particularly true for adolescents. Parental involvement in all aspects of a minor's health care is a highly desirable goal, and when confidential services are initiated, involving parents in the situation should always be encouraged but not mandated. In fact, parents and responsible health care providers share a common goal--insuring that the young person does not come to undue and unnecessary health harm. Rather than creating an adversarial situation, we consider our stance appropriately supportive of normal adolescent autonomy and growing self-responsibility in their medical encounters and in their consent to release of records dealing with those encounters. From a developmental perspective, then, the need to provide minors with some form of control over their health care and their medical records is obvious.

But our argument goes beyond that. We would also submit that pragmatic need weighs heavily on the side of that same recognition. We are all aware that adolescents are ever more in need of obtaining medical care under confidential circumstances for a variety of reasons. To fail to provide such an opportunity forces potentially harmful delay in their seeking care or even in their obtaining care at all. Health protection and the removal of those barriers which obstruct the obtaining of necessary health care is a preeminent concern and takes precedence over all other considerations.

If indeed you are willing to accept the thesis that some adolescents need access to health care on their own, if their health is to be protected, then the implicit need for confidentiality must be consistent throughout the health care system: e.g., entry into the system, in the health care transaction itself and in the documentation of that transaction in the health care record and the various purposes to which this is put. If minors' parents have unlimited access to the record, it is evident that all other aspects of a young person's privacy needs will be breached.

Additionally, after addressing the pragmatic need of minors, we cannot ignore their rights in regard to their medical records. We contend that parents are their offspring's advocates in the exercise of these rights only until such time as the minor is capable of exercising them independently and that that capability should be determined by developmental competence rather than arbitrary age. Federal legislation should recognize that current definitions of the age of emancipation are expanding both in terms of specific state law and in broadening basic concepts. Many states emancipate minors for health care purposes at an early age (e.g., as young as 14 in Alabama, 16 in several other states); some states do so on the basis of life-style (marriage or parenthood); others simply base the judgment on the minor's not living at home; and yet another group of state statutes incept the developmental concept by permitting a minor who is sufficiently mature or intelligent to appreciate the nature of the services involved to consent. Unless addressed by legislation, the current permissions extended to some minors to consent to health care will not extend to control of the recorded information resulting from that same care. That is patently absurd.

This brings us, Mr. Chairman, to the difficult task of offering a specific definition of when a minor should begin to assume the rights of which we have been speaking. Since maturity is an abstract principle in many respects and is difficult, if not impossible, to measure specifically, one must deal with age in significant measure if other parameters are too vague or too specific and hence exclusionary (e.g., a parent, married and living away from home) of otherwise eligible youths. It is also true that the initiation of abstract thought (and hence the capacity to begin to understand the implications of treatment and to give an informed consent) is relatively predictable at approximately 12 years of age. Our handling of the issue must respect minors' rights, the maturation process and the involvement of parents in the handling of medical records. The Academy proposes, as the most reasonable solution to this dilemma, the following guidelines:

- Parents should have authority for consent to release of all medical records for children less than age 12,
- Parental and minors' consent both should be required for record release for patients between 12 and 14, and (This is supportive of the developmental process of decision making and problem solving in a guided manner.)
- All minors 15 and older and those under this age who have given sole consent to health services and/or have conveyed confidential information documented in the record should consent unilaterally to the release of their record.
- Persons under the age of majority (as determined by the jurisdiction within which the provisions of this act are being exercised) and eligible to exercise rights conjointly or independently may elect to waive these rights and assign them to parents, guardian or legal

representative or, in the absence of such an individual, to another adult of the minor's choice (N.B.: to cover instances of minors not living at home or otherwise functioning in an independent manner where they may wish to have an adult act for them, but not the parent).

Each of these guidelines (which are expressed as an amendment to H.R. 2979 in an appendix to this testimony) should be administered within a framework stressing that consent be informed and that access to records and the right to challenge those records if not accurate be available. An additional safeguard should be built into this system by requiring that, for any medical information released without a minor's consent for any reason, a copy of the release form be retained in the minor's health record. This would guarantee that, at such time as the minor assumed control over his record, he or she would have a record of that information which had been released without his or her knowledge or consent.

Another issue with which we must deal in this legislation is the periodic expungement of medical information held by third parties as well as medical information which is either no longer relevant to the patient or no longer needed by such third parties. Such a provision is necessary if we are to prevent many of our children and youth from becoming virtually labeled for life in a manner over which they have no control as having some sort of condition which could evoke secret discrimination. Such diagnoses as minimal brain damage, epilepsy, malignancy or heart disease in a child; or drug overdose or out-of-wedlock pregnancy in an adolescent, may well serve to deny employment, insurance or some other such need many years hence, even if these conditions are cured or are no longer relevant. One need not even conjecture on the repercussions which psychiatric diagnoses might cause, and such diagnoses often simply stem from a transient adolescent adjustment reaction.

In view of the potential longevity of children's and adolescents' health records, any legislation also should contain provisions for periodic review, updating and expungement by both parents and minors. We should encourage revision of diagnoses in light of changes in medical status, and periodic annotation of the permanent health care record as to what material is no longer relevant for present or future health care needs. Accordingly, we recommend an amendment requiring that any medical information released to a third party payer be expunged after a period of 10 years for a patient less than 12 and/or for a minor of any age who has not personally consented to that release for any reason. We would propose a five-year post-attendance/matriculation limit on retention of medical records by service providers such as schools, day camps, Head Start and Job Corps programs, foster homes and similar institutions. We do not propose expungement requirements for private physicians, and hospitals and primary care clinics, or when the primary health care record is not held somewhere else.

Although an adjustment to the legislation under consideration which would deal with minors' rights and expungement--and, of course, with the

actual confidentiality of records--would be a step in the right direction, we have other concerns which we would propose to identify as future areas of action. We consider this necessary because of the parallelism among so many of the issues under discussion.

Mr. Chairman, once we have recognized that minors have independent rights and needs with regard to the release of their medical records, and we have taken steps to guarantee confidentiality, we must sometime in the future come to grips with several other related issues. Allow me to briefly outline what lies ahead in any thorough treatment of the problem.

One of these "touchy areas" has to do with physicians, parents and other minor patients each having information in the written record which they consider privileged for themselves alone. Parents may not wish a sick child to know about certain upsetting aspects of his disease. They often will not want to divulge their confidences on compromising circumstances surrounding the patient's birth or on matters of family discord. Other sources of potential conflict between the confidential interests of mothers and fathers vis-a-vis their children are clearly addressed in child abuse laws.

Adolescents wishing to obtain medical care for sensitive and highly personal matters pose the case from the opposite view. Teenagers who seek help for drug abuse, venereal disease or pregnancy will often consider such treatment to be wholly their own affair. Indeed, the perception that minors are entitled to privacy in health care, apart from their parents, is increasingly supported in both case and statutory law.

Physicians, too, have vested interests in this matter; they tend to consider health care records their own and choose not to make them available for patients' or parents' review. Certainly there is merit in the argument that exposure of patients or parents to potentially distressing diagnoses or highly confusing technical reports would only cause unnecessary alarm. And many physicians also wish to preserve the confidentiality of their own observations and thoughts in such entries as "highly neurotic and over-protective mother" or "suspect this adolescent is using drugs."

These situations demand that we recognize that the disclosure interests of the parent and the child or adolescent are not necessarily in consonance. We must think in terms of specific provisions requiring minor consent to release of information confidential to the minor (e.g., sex or drug counseling) and for parental consent in circumstances affecting parental confidentiality (e.g., indications of family discord). Admittedly, developing specific mechanisms to implement these concepts will not be easy, but we must keep separate the respective confidences of parents and minors whenever such separation is consistent with health care goals. One can foresee that this will necessitate the construction of some sort of bipartite document.

The confidentiality issue is further complicated by the Family Educational Rights and Privacy Act of 1974. Under its terms any written information now conveyed by a physician to primary and secondary schools receiving federal funds now bears a firm potential for being revealed to parents at any time. This law provides that parents of a student under the age of 18 may challenge any entries therein. Upon reaching the age of 18, the student assumes this right himself. Under Health, Education and Welfare (HEW) guidelines, one must conclude that this also pertains to such health information as might be held to influence the student's educational course. While reasonably well-designed to curb the many flagrant abuses of educational records in general, in the matter of health data this law fails on two counts--it makes no provision for consulting or advising the physician who submits the documents, and the student's own confidential matters are not protected against parental discovery, even when the medical sector is so enjoined by law. Rosters of those screened for sickle cell anemia or venereal disease, or notations revealing medical confidences given to a trusted teacher (e.g., female student believes she is pregnant and confides in a teacher in order to obtain help) must obviously be protected from disclosure.

One noteworthy attempt to recognize minors' requirements for special protection is contained in HEW guidelines relative to access to medical records in accordance with requirements of the Federal Privacy Act of 1974. In these provisions, minors may gain access to their own medical records as if adult; e.g., they are to be advised upon request that such a record exists and are to have a copy of the record sent to a designate of their choice for interpretation. However, if a parent makes such a request for the minor offspring's record, they may not be advised whether a record does in fact exist, but may ask that any record--if it does exist--be sent to a parental designate. In this instance, however, the designate must be a non-family-member health professional. The latter is to be advised to consider the possible effects upon the minor and his family of revealing the record's contents, and the minor notified of the parental inquiry, if possible (e.g., his whereabouts are known).

Another federal effort relates to Drug and Alcohol Abuse guidelines for this same Act. Here minors and parents both must consent to information release unless state laws permit the minor to consent to services on his own when information release consent devolves on the minor himself. In parallel, minors alone are to consent for federally funded services in states permitting self-consent for drug abuse services in general, and parents may not be notified without the minor's consent. Where no such laws exist, the first visit for the purposes of inquiry or application for services is to be confidential and may not be released to parents unless the minor is deemed irrational and in imminent danger of serious health risk. Additional services, however, are not to be provided without parental consent.

Admittedly, these are cumbersome efforts, but they are examples of various federal approaches relative to mature minors. It should be noted, however, that neither state nor federal laws or guidelines have addressed the privacy problems of younger children or adolescents relative to other third parties.

What this all adds up to, Mr. Chairman, is an endorsement for what we consider to be a much-needed first step to guarantee the confidentiality of medical records. But we cannot leave this hearing under the dangerous assumption that our job is done. I have attempted to stress in this statement the conceptual parallelism that must exist among the multitude of issues which fall under the privacy concept--and the lack of parallelism in reality--and I would submit that each of these issues must at some future time, in some future legislation, be resolved. We must deal with consent not only as it pertains to the release of records but also in terms of consent to care. At what age and under what circumstances should a minor be able to act independently in his health care transactions? We must deal with confidentiality not only as it pertains to the general protection of medical records but also as it must take into account the respective confidentiality interests of patient, parent and physician. And we must also deal with payment practices and their effect on consent, access to care and the confidentiality of medical records.

Mr. Chairman, the American Academy of Pediatrics and I thank you for this opportunity to express our views. We believe that the adoption of the proposals which we have offered here would be a significant step toward protection of the individual's right to confidentiality and privacy and that this legislation will also serve to educate physicians regarding the complexity of these issues. We offer our assistance should it be needed in the future.

Academy of Pediatrics recommended amendments to H.R. 2979,
Federal Privacy of Medical Records Act

Section 103, Page 8, line 10: The rights and obligations of a minor individual pursuant to all other provisions of this act shall be exercised and discharged as follows:

- (1) Parents, guardians or legal representatives shall represent a minor child under the age of 12 years unless (i) said minor was the sole consentor to the health services which are the subject of the health record in question or (ii) the health record contains information confidential to the minor alone. In the latter instance(s), the minor in consultation with his primary health professional or other appropriate non-relative adult shall determine a suitable course.
- (2) Minors between 12 and 15 years of age and their parents, guardians or legal representatives shall jointly and co-equally exercise all rights including but not limited to co-consent for disclosure unless (i) the minor was the sole consentor to the health services which are the subject of the health record in question or (ii) the health record contains information confidential to the minor alone. In the latter instance(s) the minor shall exercise all rights independently.
- (3) Minors of age 15 years or more shall exercise all rights independently.
- (4) Persons under the age of majority (as determined by the jurisdiction within which the provisions of this act are being exercised) and eligible to exercise rights conjointly or independently may elect to waive these rights and assign them to parents, guardian or legal representative, or, in the absence of such an individual, to another adult of the minor's choice (N.B.: to cover instances of minors not living at home or otherwise functioning in an independent manner where they may wish to have an adult act for them, but not the parent).

Mr. ENGLISH. Mr. Kindness.

Mr. KINDNESS. Thank you, Mr. Chairman.

I have no questions, but I think this is a very important area for us to be quite careful about in terms of this legislation. I certainly do appreciate your views and your testimony.

Dr. HOFMANN. Our written testimony does make substantive suggestions as to specific provisions that we think might answer some of the problems, not all of them, obviously.

Mr. KINDNESS. That is very helpful, too.

Mr. ENGLISH. Are there any questions?

Mr. GELLMAN. There appears to be a conflict between children and parents on some aspects of medical records privacy. For certain sensitive types of treatment, birth control, venereal disease, et cetera, if the parent has the right to learn about medical treatment given to their children, then children may be discouraged from seeking medical treatment.

Dr. HOFMANN. First, the fact of life today in society is that unless one is going to exert more control over adolescents, that there is a rising incidence of sexuality among teenagers. Drug abuse is an ever-present problem. These all have significant health detriment.

Our concern at the academy is with the health detriment. And while we would foster and encourage communication between young people in the practical sense, in the practice of it we still feel there needs to be care to prevent unwarranted pregnancies and prevent drug use from becoming abuse and prevent venereal disease from causing complications.

Obviously, if it is viewed that it is essential to have access independent of parental knowledge in the first place, then it is essential to have health record privacy. I don't know many youngsters who would go for treatment of venereal disease if they knew that while they could get in the front door, privately their mother could go in the back and read the record about it.

I think this is the kind of lack of parallelism I was speaking to and the essential need to preserve that option if we are going to protect health.

Mr. GELLMAN. The proposal that you have attached to your statement for changes in the legislation would allow a minor and his parents to exercise the right of access to records jointly, for minors between the ages of 12 and 15, I believe.

Under these circumstances, the parent could prevent the child from seeing his own record and the child could prevent the parent from seeing the child's record.

Dr. HOFMANN. We did not mean to imply that there would be a veto of one over the other, an and/or situation. There is a dilemma and a very frequent one in the whole issue and I have no substantive answer.

This is the issue of an adolescent who is admitted for some nonsensitive problem, a broken leg, if you will, or appendicitis. Everybody knows about it. It also happens that this is a girl who has been at the local family planning office and gotten contraceptives.

It is important for us to know, particularly in the instance of abdominal pain and in relation to medication, that she is on birth

control pills. This will be recorded in the record and it has to be for communication medically.

I don't know how to answer the problem in suggesting either the parent or the girl has options, or both, if you will. The only answer I have is a tripartite record. That boggles the mind.

I can only say we tried to do that in our clinics in that we had a separate piece for confidential information which would be filed separate from the medical record and it just did not work at all. It was impossible to make that separation.

I am afraid there are certain areas of minor's privacy in certain circumstances that at this time I don't see how we are going to be able to protect beyond a certain point.

So my suggestion in that was that this be granted both the parent and the minor, but not necessarily veto power of one over the other. The veto power would be left to the physician in his judgment as provided.

Mr. GELLMAN. You also propose that the right to authorize disclosure of medical records to a third party to be joint for minors between 12 and 15?

Dr. HOFMANN. Of course, there is an overall exemption of any minor who consented to care, who would then exercise privacy rights.

Mr. GELLMAN. OK. Let's talk about the routine broken leg.

Dr. HOFMANN. I think our provision also suggested that a minor could waive those rights if he wanted. I know of a lot of 11-, 12- and 13-year-old children who could not care less and say, let Mom take care of it.

I am terribly concerned of having young people arrive at 18 having no real concept of how to protect themselves and deal with their rights.

I don't know of a youngster where this would be any significant conflict with working with the parents and they would be learning something about protecting their own interests and standing on their own two feet in a kind of guided way.

I perceive your problem in that it creates a potential conflict. My guess is that it is going to enhance communication more than it is going to create controversy.

Mr. GELLMAN. Well, you may be right. I am concerned on the issue of disclosure where you may have an immediate conflict between a child and his parent. The child's signature may be necessary in order to submit a bill to the parent's insurance company. It is not too hard for any of us to conceive of circumstances under which a child would refuse to sign the form. If the signature were necessary, the parent could not submit the bill.

Dr. HOFMANN. My answer to that is that I think both are responsible, and as in consent legislation, we talk about who pays. That is just that if you are entitled to exercise rights, you also have the responsibilities pursuant to those rights. Arranging for payment is part of that.

That is why I would suggest having a waiver, in which instance the minor waives his exercise of his privacy rights if he wishes to and bestows them on the parents.

In this instance that you speak of, if the minor refused to sign, I would say, then you have to find a way of paying the bill. You don't get away from everything for free.

I think that young people also have to learn that responsibility aspect of it.

Mr. GELLMAN. Thank you very much.

Mr. ENGLISH. Are there any further questions?

Mr. KINDNESS. No.

Mr. ENGLISH. Thank you very much, Dr. Hofmann. It has been very helpful.

Again, I want to thank all of the other witnesses for giving us the benefit of their thoughts on this matter.

If there are no further witnesses to be heard from today, this hearing is adjourned, subject to the call of the Chair.

[Whereupon, at 12:05 p.m., the subcommittee adjourned, to reconvene subject to the call of the Chair.]

APPENDIXES

APPENDIX 1.—LETTERS SUBMITTING STATEMENTS REGARDING PRIVACY OF MEDICAL RECORDS LEGISLATION

A. LETTER FROM MAURICE GROSSMAN, M.D., PROFESSOR OF PSYCHIATRY, STANFORD UNIVERSITY SCHOOL OF MEDICINE, SUBMITTING STATEMENT ON PRIVACY OF MEDICAL RECORDS LEGISLATION

MAURICE GROSSMAN, M. D.
659 CHANNING AVENUE
PALO ALTO, CALIFORNIA

21 May 1979

MAILING ADDRESS
P. O. BOX 745
94302

Honorable Richardson Preyer, M.C., Chairman
Subcommittee on Government Information and Individual Rights
Rayburn House Office Building Room B-349-B+C
Washington, D.C. 20515

Attention Robert Gellman

Dear Mr. Preyer:

Your letter of May 2, 1979, and an invitation to submit a statement for the record on H.R. 2979 and H.R. 3444 was greatly appreciated. I recalled the position you and your subcommittee took at the last session of Congress on the Supreme Court decision in Zurcher v. The Stanford Daily. It was in that light that my statement was drafted.

As I explained to Mr. Gellman this morning I have been away at a conference in Canada. He reassured me that the unavoidable delay would cause no difficulty.

In addition to my statement, I am enclosing various exhibits to support my references to them in the statement. I hope that the American Psychiatric Association has already forwarded the one copy that was not available to me. They are all listed, appended to the statement itself.

Respectfully yours,



Maurice Grossman, M. D.

Clinical Professor (emeritus), Psychiatry
Stanford University School of Medicine

MG:mtt

Enc.

STATEMENT ON H.R. 2979 & 3444
PRESENTED TO HOUSE OF REPRESENTATIVES SUBCOMMITTEE
ON GOVERNMENT INFORMATION AND INDIVIDUAL RIGHTS
HONORABLE RICHARDSON PREYER, CHAIRMAN

BY

MAURICE GROSSMAN, M.D.*
CLINICAL PROFESSOR (emeritus), PSYCHIATRY
STANFORD UNIVERSITY SCHOOL OF MEDICINE

May 21, 1979

Mr. Chairman and honorable members of the committee, may I thank you for affording me this opportunity to present my personal views on the issues involved in H.R. 2979 and H.R. 3444. Previously, I have mailed to you information and supporting data on S. 865, a bill that covers nearly identical grounds. Perhaps it would be best first to establish my credentials. Part is established by my title given above. This would underscore that my views first developed in witnessing actual damage to patients in psychiatric care. The damage resulted from careless handling to actual volitional abuse of confidential data about such patients. The data may have been obtained either illegally or misused when the data was supplied for other purposes required by the patients. (Examples in Task Force Report #9 of the American Psychiatric Association.)

*P.O. Box 745, Palo Alto, California 94302

My involvement first began in 1960 when I was President of the Northern California Psychiatric Society (NCPS), a District Branch of the American Psychiatric Association (APA). It continued when I was Chairman of the NCPS Committee on Confidentiality and then Chairman of the APA Task Force on Confidentiality as Related to Third Parties. The discoveries and suggested solutions are reported in the above mentioned APA Task Force Report #9, "Confidentiality and Third Parties," June 1975; and obtainable from the APA in Washington. My reputation as an advocate in this area is well established in the California Medical Association, where I was a Delegate for about ten years until 1979. This had carry-over to the American Medical Association. In October 1973 I was in attendance at the World Congress of Medicine in Munich, Germany, where the protection of medical data in computers was the sole topic of that Congress. I will refer to that later. In June, 1978, I was invited to give the opening address at the Annual Meeting of the Syndicate de Psychiatres Francais in Reims, France, on Psychiatry and the Law. I have just now returned from the Third International Symposium on Law and Psychiatry, where I was invited to be a discussant of the various papers. It was held in Vancouver, B.C., Canada, May 10-13, 1979, and attended by eminent psychiatrists and legal scholars from Canada, the United States, and Europe.

I have read widely of history, psychiatry, and to a lesser extent of law, in the course of almost twenty years of activity in the area concerned in H.R. 2979 and H.R. 3444.

H.E.W. has received quite a few communications from me protesting the volitional disregard of Congressional intent via directives and simple

agency procedures. On the other hand, such agencies as the Federal Trade Commission, the Bureau of Standards, and the Federal Privacy Protection Study Commission have sought out and welcomed my input into their deliberations about these areas. Legal and medical authorities whom I consulted about S.865, applicable also to H.R. 2979 and H.R. 3444, have agreed that the Senate Bill is incorrectly labeled a protection bill for private medical records. They agreed that it is blatantly a medical record disclosure bill, hidden behind two needed protection reforms.

It is on this basis that my discussion will establish that the real issue in these three bills, ignoring differences that are therefore peripheral, is the preservation of the Bill of Rights. I will trace the growing attack on our Constitution from H.E.W., The Supreme Court itself, to the President, and the collusion of the press, in spite of the loud outcries from the latter. I will then propose a very simple alternative that will establish the two needed reforms without violating the Bill of Rights. More important, I will suggest additions to clearly establish for history, that when the Bill of Rights was threatened by two-thirds of the government sworn to protect the Constitution, with the news media maintaining a conspiracy of silence for their own ends, only the Congress exercised the courage to state the principles that would preserve the Bill of Rights into its third century.

First, it is important to record that the three bills in question stem from drafts worked over by H.E.W. for the last two years to create statutory support for violations they have been carrying on for longer than that time. I will then establish that the attack on the Bill of Rights in Zurcher v. The Stanford Daily (S.D. decision) is relevant to

H.R. 2979 and H.R. 3444. For this please note Marianne Means' story in the S.F. Examiner of December 17, 1978. How would the press hide their support for the President's limited bill for protecting the news media from the S.D. decision, after openly confirming that the decision threatened other Fourth Amendment rights far beyond the press itself. The "how" is best told by the S.F. Chronicle of April 3, 1979. The ban on news room searches, and not on other searches, was smothered in the story about legislation proposed by the President "seeking more privacy for citizens" (emphasis added). This refers to S. 865, and by extension to H.R. 2979 and H.R. 3444. Nowhere have the news media reported that the President's bill actually destroys what little privacy of medical data has withstood the onslaught of H.E.W. and the insurance industry. And that H.E.W. has been waiting at least two years for a moment when the press might be silent if H.E.W.'s bill were introduced. Further, the President's bills give statutory support for the very searches that the Supreme Court sanctified in the S.D. decision. That fact of the S.D. decision resulted in a nation-wide outcry in the press and the Congress in 1978. In 1978 there was unanimity that the Bill of Rights was imperiled by that decision. May I refer to the reports from your subcommittee of June 1978, and Senator Bayh's subcommittee on the Constitution of the same period.

I will not again repeat the story of the history of the Bill of Rights' formulation and adoption. It is important to reassert that the impetus was to protect the individual citizen from his own government created by the original articles of the Constitution. This stemmed from remembering how Government, in the name of "law and order," violated

"inalienable rights" that led to the Declaration of Independence and its list of indictments explaining not only the need but the duty to separate from England. Now, again, we are faced with an onslaught on our inalienable rights, including privacy, with search and seizure, and threats to our medical welfare, supposedly protected by the concept of "life, liberty, and the pursuit of happiness," in the name of "law and order," in total disregard of the Bill of Rights.

Even if physician-patient privilege has been weakened by the legal profession, psychotherapist-patient privilege has been upheld as a constitutional right by the California Supreme Court, and other appellate courts; and by the Committee that formulated the Proposed Code of Procedures for the Federal Courts, in its Rule 504. While the Rule 504 was rejected as such by Congress, it does exist in seven states, and therefore in the Federal Courts of those jurisdictions. Is the Subcommittee aware that a search of the Stanford Psychiatric Clinic--in order to prevent a defendant from having access to support for the defense--was part of the Stanford Daily case in the trial court? Has the news media publicized that since the S.D. decision, that same District Attorney secured search warrants on attorney's offices, including that of the Public Defender of his same county? Need one conjecture how the current U.S. Supreme Court would rule on the question of whether such action interferes with a defendant's right to a fair trial? This court has ruled that a Prosecuting Attorney is immune from any civil action even though he knowingly used perjured testimony to secure a conviction. Mary McGrory headlined in the Palo Alto (Calif.) Times of June 26, 1978, "That government can do no wrong" according to the U.S. Supreme Court.

In her indictment she includes Stump v. Sparkman. The dissent conveys the horror better than I, for the case where a judge ordering the sterilization of a girl, is held blameless. The Majority rested its decision on there being no statutory prohibition of that act. How many acts are not specifically prohibited? The existence of the Bill of Rights was not enough for the Majority. Whalen v. Roe is another example. The majority blandly stated that the State of New York assured the records were amply protected from disclosure. The news is full of stories of such promises where there is no such protection--H.E.W. being the best example of promising security while admitting such promises are nonsense. The most frightening evidence is footnote 8 in the S.D. decision itself. The Supreme Court majority state that the search warrant was justified because with a subpoena a defendant might claim the protection of the Fifth Amendment. I suspect the Court would repeal all ten amendments on such reasoning that they interfere with "law and order." This is not surprising if one reads that decision in full, and finds how history itself is distorted to create a tortured reasoning supporting the Majority's findings. Shades of 1984!

Then comes the President's package "to undo the harm of the S.D. decision," which his Justice Department supported. The President himself, quoted in the S.F. Chronicle of April 24, 1979, suggests he must be familiar, along with H.E.W., with what he describes. "Carter says foes 'hoodwinking public.'" He suggests an oil windfall profits tax bill is "in fact a charade." What better way to describe his sponsored bills, starting with S. 865, labeled by that same S.F. Chronicle "Carter seeks more privacy for citizens." Reading stories across the land in

addition to that in the Chronicle suggests the news media, by its silence, if not the actual distortion in the Chronicle, is in collusion with the Executive Branch to "hoodwink the public" with a bill that is "in fact a charade." If the bills in question, S. 865, H.R. 2979, and H.R. 3444, are passed as now written, there is no more privacy of medical records; what little psychotherapist-patient privilege exists will be destroyed by statute; and governmental control over citizens becomes more grievous than the country from which we separated; a continuation of abuse already looked at askance by French physicians and lawyers familiar with the lack of what they hold inviolate--"medical secrecy"; and not different from practice in totalitarian states. Only representatives from the latter governments at the World Congress in Munich in 1973 openly declared they could not understand the concern of the free world about the threat of medical record privacy in this age of computers.

For the details, I will address myself only to H.R. 2979, because in the above respects H.R. 3444 is not different enough to matter.

H.R. 2979

Findings and Purposes

I would emphasize Sec. 2(a) states that the protection is a Constitutional right; and 2(a)(2) states the mere presence of some information can threaten that right. It is true that this need must be balanced against public needs and the right of private organizations for legitimate needs in all fields.

I am all too familiar how the insurance industry has demanded full access to entire hospital records; has dictated length of hospital

stay, sometimes with disastrous effect on sick patients. The misuse of such records to find an obscure phrase to justify denying legitimate claims should also be investigated. The only recourse that people then have is to go to court, where the legal costs are prohibitive. Courts never award attorney fees or costs when a claimant wins a claim for which they have paid insurance. H.E.W. has always so complicated forms for Medicare claimants that many of them just give up. The data that H.E.W. has is made available to any government agency. They even admitted they placed computer terminals in at least two offices of private insurance companies, thereby giving them full access to H.E.W. records. The hearings and final report of the Privacy Protection Study Commission has documented how far the insurance industry, and the fact gathering industry that serves them, can be trusted with the security of medical data. The Task Force Report #9 of the A.P.A. gave examples of actual damage to patients from disclosure of intimate details, including the mere disclosure of a diagnosis, or the fact of being in psychiatric treatment.

Further, courts have ruled that there is a constitutional basis for the psychotherapist-patient privilege that would protect against any demand for the confidential data associated with treatment. At least one court has ruled that insurance today is such an integral part of medical care, that any privilege involved with medical data is not waived simply because of any revelation incident to claims on that insurance. In this respect, some companies have been able to function with almost no information other than the name of claimant, of supplier of treatment, and nature of treatment (see Judge Hofstadler's dissent

in Caesar v. Mountanos). In France and England, insurance health care claims require no more than that. Here some companies have demanded two pages of intimate questions be answered before they would pay a claim. It would be well to specify how little is the legitimate need for information. It is in this light that the President's bills need to be seen as disclosure bills.

Research

Sec. 101(8)(A)&(B) the term "research," especially "scientific or medical research," has taken on a holy connotation. May I bring to mind that the Tuskegee Syphilis Treatment (or non-treatment) project was the result of medical research. The MANDUCS project for Federal Employees insurance coverage in the District of Columbia, made very sensitive psychiatric data available to governmental agencies, also in the name of research for NIH. The Mental Health Law Project reported leakage of data. To the best of my knowledge, I believe it was finally determined the information supplied no useful results. In California, sensitive information about women was made an obligatory part of birth certificates, without any control from the mothers involved. You might ask the women of California what they thought of such research. The S.F. Sunday Examiner & Chronical of April 2, 1978, reported that "A questionnaire by bureaucrats to learn intimate details of the sexual lives of welfare mothers, has been 'thrown in the garbage.'" This research was prepared "in an attempt to satisfy federal requirements for information in Aid to Dependent Children cases." Angry senate legislators killed it. Can you picture yourselves as being held responsible for allowing such research in the future designed by Mr. Califano? The important factor

is that as written the bill makes the fox (H.E.W., the insurance industry) the guard over the chickens (us).

Of course research is important. But it can be protected, and identifiable disclosures obviated. This was discussed at length at the Munich 1973 conference, is still being debated in Britain, and in the United States. I have covered this in my article "Confidentiality in Medical Practice," 1977. A review board should have power to determine the value of a project; whether identifiable data is necessary; how to put blocks in the process so followup data can be obtained without disclosing identity to the research group. Most important, such a board should not be connected with the institution seeking the project.

Sec. 111(a)(3)--one of the current abuses is of insurance companies copying entire medical records under threat of not paying; or delaying payments to hospitals for months, sabotaging the cash flow necessary for hospital functioning. The wording here gives statutory approval for such practices. This is not protecting the patient. It suggests the insurance industry as well as H.E.W. had a hand in writing the bill. (This is especially true of S. 865, where two words open all doors for the insurance industry as well as government, in the exception Sec. 105(b)(22).)

Sec. 114(3)--Who determines what is needed? As I have noted above, in Britain and in France, they function with NO information other than the facts incident to billing, not medical data. I wonder why Britain and France seem to be more honest than implied about the United States by our own government? Or do they simply have a better system that would not require the elephantine monolith of H.E.W.? Some good

exploring by one of your committees might find a way to drastically reduce the expense of medical care, by eliminating some overhead.

Sec. 125--Audits and evaluations can be done at treatment sites without removing any record that is identifiable by patient names. Hospital review and accreditation units now function that way.

Sec. 127--This section reveals that "record" is not defined in section 101. In line with the skepticism I have expressed, I wonder if this was inadvertant or not. Statutorily mandated disclosure is usually of one isolated fact, plus identity of the individual, e.g., a communicable disease, seizure for drivers licenses, wounds from firearms or stabbings, an abused child. If there are other public health needs that cannot be followed up from such simple disclosure, I am not familiar with any that would require an entire record to be disclosed. Some agencies have the tendency to do just that, not supported by law. The protection of Sec. 127(b) is meaningless with the exceptions written into it. From there on, H.R. 2979 pursues the faults of S. 865, permitting search and seizure even without a subpoena or search warrant in most cases. In rejecting Rule 504 of the Proposed Rules of Procedure, the Congress refused the psychotherapist-patient privilege rule, even though it does rest on Constitutional grounds. In Alaska, in Allred v. State, even common law was given as a basis of such privilege where none existed by statute. Section 130 and 131 would in a sense destroy the reality that courts do find there are grounds for such a privilege. This fact alone demonstrates what a "charade" and "hoodwinking" goes into the publicizing this as a protection of privacy measure. If challenged in court on constitutional grounds, one can predict how the

current Supreme Court would make short shrift of an appeal to the Bill of Rights. After all, it has publicly stated it would not approve any defendant relying on the protection of the Fifth Amendment.

I also note that Section 141 duplicates the invasive aspects of S. 865; and especially (C) of not letting the patient know his records have been obtained. This too smatters of what I would call that infamous footnote 8, that repeals the Fifth Amendment without any outcry from anyone.

I am sure you are in a better position than I to judge whether the average citizen has the resources to utilize the few protective features the bill makes available to him, in place of the Bill of Rights. Also, with today's concern about the costs of medical care--with H.E.W. never acknowledging how much its functions add to the cost--your staff could estimate what extra burdens on hospital overhead will result from carrying out the mandated processes of this bill. As I indicated originally, these comments refer specifically to H.R. 2979, only because I view H.R. 3444 more invasive and voiding more individual rights.

I would recommend the following positive features for a bill whose purposes are the protection of medical information.

1. The right of access to one's records for review and correction is a well supported doctrine leading to better medical care. The inclusion of using a third party, if the information would be damaging to the patient, or innocent third parties, should be included as these bills do. I cannot see where this is served by having the right to copy the records a part of this. In legal actions there are other ways for achieving this.

2. The disclosure of medical records should be by the patient's or his representative's authorization only, EXCEPT AS PROVIDED BY EXISTING STATE OR FEDERAL LAW, THAT IS NOT IN VIOLATION OF THE BILL OF RIGHTS. This should take care of all statutory obligated reporting. It would cover all the legal requirements in H.R. 2979 that have justification, and would not open the whole barndoor that is needed for protection of patients' records. Anything else makes the bill, like S. 865, a disclosure bill. And, in my opinion, further destroys the fabric of the Bill of Rights.

3. To support the findings of the Federal Privacy Protection Study Commission, the details of the authorization and its limits should be spelled out as indicated in H.R. 2979.

4. For research requiring identifiable data, the bill should emphasize that most needed research, auditing, etc., can be done with non-identifiable data records, leaving identifiable material at treatment sites. Procedures for needed identifiable data have been developed (see "Confidentiality in Medical Practice"). The "watchdog" functions should be by independent boards, on a state-by-state basis, selected by medical schools, medical organizations and licensing boards of the state in question. For a nation-wide study, there could be a Federal Board, created from nominations from the state boards.

I believe the above could result in a much simpler, and overall more economic approach to the problem.

If there still be those who believe there is a place for a police state version of disclosure, may I respectfully suggest that they have the courage to submit such a bill as a separate entity under their sponsorship openly, and not hidden under the camouflage of a Protection

Bill. For those who would go down in history as a protector of the Constitution, may I suggest you consider broadening the protection from the S.D. decision to cover all citizens, not just the press. Even Philip Heymann, assistant attorney general of the Justice Department's criminal division, acknowledged before the House Judiciary subcommittee on courts, civil liberties, and the administration of justice, that all searches of third parties should be prohibited. And, moreover, that there be reconsideration for establishing Rule 504, the psychotherapist-patient privilege, as an indicator that the Bill of Rights, and the inalienable right to life, liberty, and the pursuit of happiness is as meaningful today as it was in 1776 and 1791.

Thank you for this opportunity to respectfully submit my views.

Respectfully,

Maurice Grossman, M.D.

EXHIBITS

1. A.P.A. Task Force Report #9-Confidentiality & Third Parties, June 1975
(To be delivered by A.P.A., Washington, D.C. Tel.797-4974 Mrs. Dixon)
2. Marianne Means, S.F. Sunday Examiner & Chronicle, Dec. 17, 1978.
3. S.F. Chronicle, page 1 story, April 3, 1979
4. Maurice Grossman, "Confidentiality: The Right to Privacy vs. The Right to Know" pp.137-184 in Law and the Mental Health Professions, 1978
5. Maurice Grossman, "Confidentiality in Medical Practice", pp.43-55, in Annual Review of Medicine v.28, 1977.
6. Mary McGrory, Palo Alto (Calif.) Times, June 26, 1978
7. S.F. Chronicle, page 1 story, April 24, 1979

(NOTE: Exhibits 1 and 4 available in subcommittee files)

Swift passage for Carter's press search bill

By Marianne Means
Examiner Washington Bureau

WASHINGTON — President Carter's proposed bill to protect reporters and other writers from surprise raids by police represents a political as well as legal victory for the press.

The Senate will hold the first hearings on the proposal on Tuesday and congressional approval is expected to be swift.

ANALYSIS

The administration's bill would prohibit state and federal law enforcement authorities from conducting searches without notice on the basis of a warrant in such cases or other places for notes, tapes, or other documents. The only major exceptions would be if the reporter is a criminal suspect or a life is in danger.

Police would be required to obtain a subpoena to seek documentary evidence relating to a crime from anyone planning to use it for publication. A subpoena requires advance notice and an opportunity to protest it in court, and is limited to material specifically sought. A warrant allows police to rummage freely around a room without warning.

The proposal is a response to the press outcry which followed a Supreme Court ruling in May that a police search of the Stanford Daily newspaper office for photographs of a 1971 campus demonstration was constitutional, although the newspaper staff was not suspected of any criminal conduct. In that case, the Justice Department had supported the police and argued the

press had no special right to protection against search warrants.

The administration's reversal of attitude came after an intense editorial campaign denouncing the decision. In newspapers around the country, The American Newspaper Publishers Association led the fight, which had already prompted 13 bills in Congress to override the Supreme Court on this issue.

It was not a coincidence that President Carter chose a gathering of Gannett Newspaper editors as the forum for his announcement. Gannett President Alan Naulhart is also president of the ANPA. "Carter had obviously bowed to political pressure," a news association official said happily. "It was just as though he was offering Naulhart a peace offering."

Hasty analysis of the proposal by news organizations has produced general satisfaction with it. In particular there is applause for the fact the protection would extend to state and local police, under the power of Congress to regulate interstate commerce. Attorney General Griffin Bell is a staunch believer in states' rights, and it came as a surprise that he would agree to usurp the states' traditional power to control search warrants.

The news industry, however, is faced with a delicate dilemma. It had joined with the American Civil Liberties Union to urge legislation that would also extend the search protection to innocent third parties not connected with the press who hold confidential information. The Carter proposal affects only the press and other writers.

Realistically, the Carter bill is more

likely to pass than a bill extending the protection to others, which would be strongly opposed by law enforcement groups. News organizations are uncertain whether to take the risk of looking elitist by rallying around the bill which would only protect their own newsrooms or take the risk of stalling everything by demanding a broader bill. In the end, they are likely to continue their verbal support for the latter but pass the word they are happy to get the former.

Announcing the new proposal, President Carter said he recognized "confi-

dential sources and notes are essential to the operation of the press." Further, more, Assistant Attorney General Philip Heymann, who drafted the proposal told reporters that the administration was prepared to state for the record that passive receipt of government information from a whistleblower would not make a reporter suspect of violating the Espionage Act. Breaching national security and receiving stolen property were charges made by the Nixon administration in its fruitless efforts to prevent publication of the Pentagon papers

Carter Seeks More Privacy For Citizens

Washington

President Carter asked Congress yesterday for new citizen privacy laws, including a ban on most police searches or seizures of reporters' notes, film and interview files.

The proposed newsroom search ban was intended to override the Supreme Court's controversial "Stanford Daily" decision of May, 1978, which Carter said "poses dangers to the effective functioning of our free press."

The President also proposed new restrictions on the use of medical records and records of federally financed research projects. He promised to submit soon a bill that would expand privacy laws concerning banking, credit and insurance records.

At the same time, he urged passage of a separate bill already before Congress that would limit the use of polygraphs or "lie detectors" in private employment. And he urged employers to adopt voluntary restrictions on disclosure

20 San Francisco Chronicle

★★ Tues., Apr. 3, 1979

CARTER SEEKS MORE PRIVACY FOR CITIZENS

certain exceptions — bar searches or seizure of reporters' work product by local, state or federal law enforcement agencies. The measure would require a subpoena, rather than a more easily obtained search warrant, for police searches or seizures of newsroom documents that do not contain the work product of reporters.

"This ensures that police will not rummage through the files of people preparing materials for publication and that those subject to the subpoena have the opportunity to contest the government's need for the information," the President said in a message to Congress.

The President's proposed safeguards for medical records would

give patients the right to see and correct their medical files, make it a crime to obtain medical information under false pretenses and limit disclosure of hospital records.

The bill on federally financed research records would give researchers a legal basis to promise confidentiality to persons who give them sensitive information, and would require researchers to warn their subjects of any possibility the information might be disclosed.

Carter called for a "privacy policy" to be observed by industry and various levels of government, which would allow persons to know what information is being collected about them and to see and correct their personal files. They would be

informed when an adverse decision is taken based on personal data, and would be allowed to prevent improper access to the records, Carter said.

Carter said he is issuing new guidelines for federal agencies that use computers to detect fraud or abuse in their programs.

He said investigators would be required to notify the public before any new computer search of names, and disclosure of names of suspects would be restricted. Use of the names would be limited to cases when there is no alternate means of finding violators at comparable cost.

Associated Press

PALO ALTO TIMES, Monday, June 26, 1978—9

Judge, high court view on par: Government can do no wrong

An opinion

By MARY McGRORY

WASHINGTON — If the law is "a ass," as Dickens wrote of another judicial proceeding, the law is a bully in the Alexandria court of federal Judge Oren R. Lewis.

His Honor, it became clear during the indescribable trial of Frank Snepp, III, the ex-CIA official, who wrote "Decent Interval" without the agency's permission, is really Patton in a black robe. What he did to the case was the moral equivalent of leading a tank column over it.

The government, according to him, can do no wrong. He does not care if Snepp disclosed a single syllable of classified information. The question for him is simply a breach of contract or of fiduciary trust.

The Justice Department sent three lawyers to argue the case. They were superfluous. The irascible judge did their work. "Any objection?" he would ask before Snepp's lawyer could finish a question.

"Objection sustained," he barked before the Justice Department could clear its throat.

He permitted no reading from documents that had been admitted into evidence. He was indignant that a paper marked secret had been produced for the defense.

He turned to Elizabeth Whittaker, the Justice Department attorney, in a gallant fury. "I never required you to give any secret information. They will take advantage of you whatever you do, lady or man."

Making a heavy out of Mark Lynch, the easy, buoyant, American Civil Liberties Union lawyer who was trying to defend Snepp, was something only a judge whose mind is made up would attempt. But judicial detachment is not something Lewis even makes a pass at. His preoccupation that he might be caught making any kind of judgment about the Vietnam War, the fall of Saigon or the CIA consumed him.

Like most conservatives and many individualists, the judge has a gnawing concern about protecting the powerful. The law, which has an eye out for the weak, comes second.

But if Judge Lewis' solicitude seemed misplaced, it was on a par with the kind that has lately been exhibited by the Supreme Court.

The court has, within the past three months, moved to guarantee the safety of the snail darter and the federal judge and thrown the press to the wolves.

The decision in the snail darter case, regarded separately, can be seen as a glorious victory for the environmentalist. But taken with the brusque ruling in the Stanford Daily case, which urges the press to pull up its socks and take its chances with unannounced police searches, it makes you wonder if the Constitution is, in fact, a living document.

What is grating about the two decisions taken together is the excruciating concern that Chief Justice Warren Burger reveals for the "intent of Congress" in the "Endangered Species Act" — as contrasted with the airy disregard in the Stanford Daily decision, written by Justice Byron D. White, for the intent of the authors of the Constitution when they wrote the Fourth Amendment — not to mention the First.

Burger discourses at length about the conflicting claims of laws passed by Congress — one which authorized \$100 million for the nearly completed Tellico Dam, and the other which mandated the preservation of "the critical habitat" of rare fish.

Justice White says "tut-tut" to the protest of the Stanford Daily, which was raided without warning by a police search team, even though none of the staff was suspected of wrong-doing.

White gives us fatuous, quantitative comfort: There have been "very few instances since 1971 involving issues of warrants for searching newspaper premises."

If such a decision had been on the books at the time of Watergate, there might not have been a need for the White House plumbers, and several newspapers might have been receiving the police on deadlines in their "critical habitat."

Earlier, Justice White — a Kennedy appointee, it should be remembered — gave us the doctrine of absolute immunity for federal judges. The case was outrageous: An Indiana judge, simply on request from a mother, issued an order for the sterilization of her 15-year-old daughter. The girl, who was told she was having her appendix removed, sued the judge on discovering her situation.

Justice White again took the lofty view that people shouldn't make a fuss when they fall victim to the law which presumably protects them.

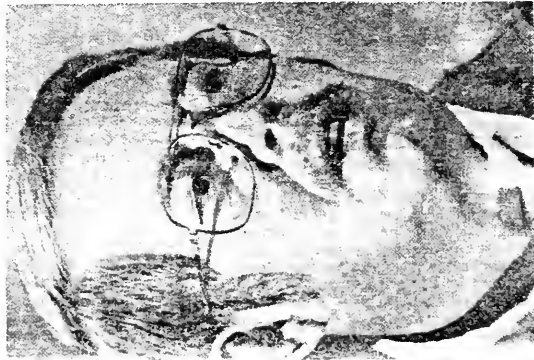
"Despite the unfairness to litigants that sometimes results, the doctrine of judicial immunity is thought to be in the best interests of the proper administration of justice," he wrote.

Justice Potter Stewart humanely dissented: "I think what Judge Stump did has beyond the pale of anything that could sensibly be called a judicial act."

San Francisco Chronicle

TUESDAY, APRIL 24, 1979

★★★★ Carter Says Oil Foes 'Hoodwinking' Public



Billy Carter, trimmed down and wearing a mustache, spoke at his first non-drinking new conference

Windfall Profits Tax Plan

Washington
President Carter said yesterday that public support of his energy plan has led opponents to try to hoodwink the American people by passing a windfall profits tax that is in fact a charade.

The president said that opponents have shifted their strategy from outright opposition to a more subtle tactic of making such a tax breakthrough.

The vehicle for this "charade," Carter said, is a "blowback" provision that would enable the oil companies to escape the tax by putting their profits into development of new energy sources.

"It isn't a 'blowback.' It is a 'blow under' and a 'kickback,'" the president told the annual meeting of the National Academy of Sciences.

The president told the audience of scientists and engineers that opponents of his proposed tax plan are in the painful situation of relying on a greedy and unreliable foreign cartel for nearly half the oil we use," Carter said.

"Many of those who only a few weeks ago were dedicated to felling outright the windfall profits tax have now grown so frightened that they are reflecting the views of congressmen who returned yesterday from their Easter recess."

In merely three weeks, the outlook for such a tax has undergone a surprising reversal. Virtualy written off by many political experts the day that it was proposed, the tax has found a new ground in the eyes of observers, appearing to include the president, now believing that the only question is the form that it will take.

"The battle is far from over," Carter said.

The president has directed the gradual implementation of price controls on domestic crude oil, beginning June 1. He asked Congress for a tax on the resulting "windfall profits" as part of a complex, controversial plan to end America's dependency on foreign oil.

The proposed tax would be in two stages. The first would be on the difference between current world oil prices and world oil prices as they now exist. This tax would be phased out gradually over a period of 60 months.

The second stage would be a tax on the difference between

Back Page Col. 3
From Page 1

current world oil prices and future world oil prices. This tax also would be temporary, but the length of the duration has not yet been proposed by the White House.

On another front in the energy battle, the president used unusually strong language to demand that the strong support of Petroleum Exporting Countries.

"Oil remains by far our most important energy source, and we are in the painful situation of relying on a greedy and unreliable foreign cartel for nearly half the oil we use," Carter said.

"As that crushing river of foreign oil flows into our country, a river of money flows out, threatening the health of our economy, the stability of our currency and even the security of our nation," he added.

The president asked the scientific community to help him find an energy source that would enable the United States to fulfill the trust of the American people by creating the new energy technologies that are vital to the future well-being of our nation.

Carter also made a plea for support of a strategic arms limitation treaty with the Soviet Union.

"We have lived too long with nuclear weapons," the president said. "We have grown too accustomed to their shadow, now not to forget our history. We must not let the ultimate horror would be."

Today Powell, the president's press secretary, told a news briefing that Carter needs the support of "powerful" and "influential" institutions in order to gain Senate approval of SALT II, the arms treaty now being negotiated.

Powell said that the president could not do the job alone.

"It will not be approved by the Senate without this. This is the president's responsibility, and his name," Powell said.

"This society has a wide variety of institutions that exercise considerable influence on the actions of government," the press secretary added.

Powell declined, however, to identify the institutions that he said the White House expected to play a role in supporting SALT II.

New York Times

CONFIDENTIALITY IN MEDICAL PRACTICE

◆7221

Maurice Grossman, M.D.

Department of Psychiatry, Stanford University School of Medicine,
 Stanford, California 94305

For his patients' sake and increasingly for his own as well, the physician would be well advised to learn the narrow but tortuous path between the edict "reveal not your patients' data" and growing demands that he do just that.

BACKGROUND

The Greeks started it! Many medical concepts of the fourth century BC and after were attributed to Hippocrates. Some were products of his followers, with credit given to the Hippocratic school. The Hippocratic oath was essentially a code of ethics credited to the Pythagoreans. They promulgated a strict code of social and moral ethics in reaction to the less concerned standards of their society and of other medical groups (1). The more disciplined attitude, inferring that less rigid practices were current, suggests that during the fourth century BC physicians were not above gossiping and revealing their knowledge about patients to recipients whose concerns were not for the patient. The Hippocratic oath also adjured the physicians against giving poisonous drugs to those requesting such drugs. While Edelstein deduces that the intent was to forestall suicide (1), the language also suggests that the recipients of the poison might intend to administer it to someone else. The concept of "poison pen" material is not too farfetched in application to confidentiality.

In the closing quarter of the twentieth century AD, concern about physicians gossiping and releasing medical information to others is still with us. Currently, medical care involves many adjunctive professionals in supplying health services. They need access to this medical information. Social attitudes have changed—mostly superficially. Two major factors have not changed. Firstly, personal information is still necessary for determining health care in treatment and prevention of illness and trauma, and for research to improve the whole process. Secondly, some of the personal data can be poisonous to the patient, depending on who uses it and how it is used.

Everything would be simple, were we guided merely by the tenet "Do not reveal anything to anyone." Unfortunately, confidentiality cannot be absolute. The patient might require and therefore request revelation of some facts in order to get benefits based on the information. Others—family, schools, and even employers—could use some information to help the patient to overcome his disability. Here too, the patient should consent to the disclosures. There is divided opinion about whether it should be done without the patient's consent when he is not looking after his own health interests. There are situations where society's overriding needs and rights demand violating the patient's rights to privacy and, therefore, confidentiality (2). One must ask who determines these overriding rights of society, and what the basis is for that determination. These complications set the stage between the right to privacy and the need to know, with no clear delineation. As the tortuous path is followed, note that "the need to know" becomes "the right to know."

The Hippocratic concept is commingled with the popular attitude of society, accepted by many physicians, that medical information confided by the patient or discovered about the patient will never be divulged. This sacrosanct concept is supported by laws requiring such observance under threat of criminal and civil consequences for violation. As usual, this legal demand allows exceptions when the law wants such information (3). In 1828 New York was first to enact protection against legal demands for this sensitive data. New York was soon followed by most other states. The legal onslaught continued, with breaches in this protective barrier through nibbling exceptions created either by legislative act or judicial decision. As late as 1960, the major admitted threat to protecting patients from disclosure was the power of courts, legislatures, and other branches of government (4). The process of legal erosion has reduced this protection—physician-patient privilege—to virtual impotence (5).

BASIC DEFINITIONS AND CONCEPTS

Certain definitive differences must be considered in threading one's way through the problems. "Privacy" alludes to personal investments that must not be intruded upon by others. The individual may relinquish this right in many ways. In confiding some private aspects to another, the individual may explicitly or implicitly exact an obligation that the recipient keep this confidential. Thus "confidentiality" implies this obligation. As in medicine, it may imply that the disclosure was made to the second party to fill an urgent need. The second party has no proprietary right to the private material. If certain legal requirements are met, this confidential exchange can be protected legislatively from legal demands (6). This information is then privileged and leads to "physician-patient privilege," "psychotherapist-patient privilege," "attorney-client privilege," etc.

The above sequence from privacy to confidentiality to privilege does not alter the basic premise that the information is about an individual who alone maintains the proprietary right to that information. Having that right also leads to the corollary that that individual alone has the right to disclose this private information, while others do not. He may authorize other holders of the information to reveal it to third

parties for whatever reason that impels the owner of the private material to issue the authorization.

A trap for the unsuspecting one is the surrender of privacy implicit in his making his data public. Usually the data subject authorizes release of information to secure certain benefits. This may be done willingly, e.g. to seek exemption from military service, or unwillingly, e.g. to obtain insurance benefits that will be withheld if permission for getting medical information is refused. The wording of authorizations may be so broad that the patient has waived all rights to forbid dissemination of the material. When the patient authorizes a release of information to a government agency, he may be unwittingly releasing it to files that are legally public records, available to anyone. In court, if the patient or his attorney makes reference to medical-record details, he may have waived privacy voluntarily, and thereby his right to privilege and its protection (7).

INSURANCE INDUSTRY INTRUSIONS

Legal demands for medical information, usually by subpoena (sometimes by search warrant), are relatively infrequent. However, since 1960 the growing increase in insurance coverage for medical-care costs has been accompanied by increasingly frequent requests for medical information to justify claims for payment (8). An insurance policy is a contract with specific limits and restrictions. The insurance carriers need information to determine that the claim is for services within the limits of the contract. Each claim form has a paragraph authorizing release of medical information, to be signed by the claimant. With few exceptions, the authorization is relatively unlimited in the breadth of disclosure the carrier can seek. It does not limit the dissemination of the disclosed information. It sets no criteria for the ultimate fate of the revealed information. Refusal to give this unlimited demanded information has resulted in refusal to pay claims that are otherwise justified.¹ The insurance carrier takes the position that it alone can determine how much and which information is necessary to justify claims payment. Medical information irrelevant to the cause for the claim has been used to justify the invalidation of the obligation, suggesting one reason for wanting an unlimited authorization (9). Some insurance companies do this with medical information obtained illegally (10).

Since most medical-care insurance is under group industrial policies, medical information released by patients to an insurance company has reached employers and, through employment channels, fellow employees. The risk to employment, promotion, character attacks, and emotional shock related merely to the public

¹When Stanford University Hospital refused to permit a Blue Cross employee to be stationed at Stanford and given access to patients' records to determine appropriateness of length of stay, Blue Cross started delaying reimbursement. This forced acceptance of Blue Cross's demand in June, 1976. When Blue Cross of Georgia withheld payments when the College Street Hospital of Macon, Georgia refused their demand for complete access, the latter sued Blue Cross. Z. Sweeney Sikes, M.D., who pursued this, reports an agreed stipulation and verdict in February, 1975, awarding the hospital the approximately \$70,000 in question.

exposure is greatest where psychiatric illness is involved, but not limited to that specialty of medical practice (11). The unlimited authorization permits such practice. In employer-administered group policies, the employee or his dependent patient may be obligated to authorize broad disclosure to the employer with no restriction of usage.

With the Federal Fair Credit Reporting Act requiring disclosure of files and sources of information, insurance companies have started informing applicants for policies that they use outside investigators—armed with a photostat of the authorization signed by the applicant—to get full medical records from all prior treatment sources, including unconfirmed information from neighbors, friends, family, employment sources, and wherever the claimant has contact. This information is stored without verification. The competition between these outside investigators leads to advertising the high percentage of adverse information they collect about investigated subjects. Since much of the information is unverified, it suggests what sort of bias may enter the collection. At least one company advertises that it stores this microfilmed data for future use without specifying to whom and on what grounds it will release the data (12). It might include records from hospitals and physicians, obtained supposedly with consent originally given to an insurance company.

However, some insurance companies will accept a simple general statement for a health-insurance claim; a verbal report to their medical director, avoiding records of sensitive data; or, in one plan, the mere statement "confidential illness" being checked obviates any other detail. When a large sum is involved, some companies will accept a peer-review decision, also avoiding written records. In July, 1976, the American Psychiatric Association and the Health Insurance Association of America began testing a code-reporting system formulated by Richard G. Johnson to avoid reporting identifiable material (13). The foregoing indicates that the problem is perpetuated by some companies and is not industry-wide. It also shows that insurance reporting can get along with less data than is prevalently "needed."

LEGAL PROFESSION'S DEMAND FOR DISCLOSURE

The demands of the law for disclosure of this confidential data has been mentioned in the preceding discussion of privilege on page 45. The original physician-patient privilege, more noted for its holes than for its protective fabric, never was acceptable to the legal profession. The severe destructiveness caused by public revelation in court of details gathered in psychiatric treatment stemmed from social attitudes about psychiatric illness as a category, the intimacy of the private details revealed during treatment, and the fact that such patients were already under intolerable emotional stress that led them into treatment initially (11). The tendency to view psychiatry as detached from medicine obscures the fact that these same problems of illness exist in every physician's practice, regardless of specialty. Every physician's patients may be subject to the same emotional disclosures and subsequent trauma. The only need for physician-patient privilege is for data that would affect

the patient emotionally if revealed to others and would in effect create a psychiatric syndrome. Courts have recognized that the protection of psychotherapeutic communications is based on constitutional rights, as well as meeting the criteria for privilege (14). Unfortunately, such legislation is still limited to California, Connecticut, Florida, Georgia, Illinois, Kentucky, and Massachusetts. Worse, they limit the protection to patients of psychiatrists and psychologists. Rule 504 of the proposed Federal Code of Evidence (5) would have made the protection available to all physicians' patients. The legal profession's growing boundaries of the right of discovery, ostensibly to bring in all the facts available to reach a just verdict, even denies this protection in the exception when the patient uses his emotional condition for a claim or a defense. It makes no leeway for circumstances where the needed facts can be obtained other than through the treatment source, even if these other sources may also be physicians. Parenthetically, the legal profession's virtuous search for the truth, breaching constitutional rights of the patient, does not extend to their own files and the truths confided to them by their clients. The legal profession's use of subpoenas and how physicians are intimidated by them to reveal information unnecessarily has been discussed elsewhere (15).

This exception to privilege compounds the insurance problems of patients and physicians. Patients who exercise their rights to withhold unnecessary data and thereby lose their benefits, have recourse only to court action. In filing a claim, they lose the protection of privilege in that action because of the exception. Therefore, they lay themselves and their medical records open to the public—a "Catch-22" situation. Similarly, when physicians are slandered for protecting their patients' interests, they cannot go to court because it, too, would mean discussing their patients openly to explain that protection.

ALL MEDICAL COMMUNICATIONS ARE NOT CONFIDENTIAL

When it was pointed out in the second paragraph above that physicians other than the treating one could give the facts necessary, it demonstrated that all professional communications between an individual and a physician are not confidential. This term applies only to those communications that are given in confidence as a necessary part for treatment. Whenever a patient knowingly goes to a physician for a report to be made to some other party, there is no "confidence." In some cases, as in court-ordered examinations, the participation may not be voluntary. Examples are medical reports ordered by current or prospective employers, applicants seeking licensure that requires a medical examination for meeting standards, and medical recommendations required for admission to certain schools. Such examinations may be as minimal as a vision test for a driver's license or as extensive as the inclusion of a psychiatric examination where indicated. It has been recommended that the report be minimally sufficient to meet the objectives of the examinations (16). Such patients should be warned that any material divulged might become part of the report. Especially when a report might lead to an adverse finding, it is prudent to

include details supporting that judgment. There is no agreement by the examiner for confidentiality. If anything, there is prior understanding that there is no confidentiality. Any agreement of confidentiality can be only between examinees and those requesting the examination. The availability of such examinations by others emphasizes that treating physicians should try to avoid supplying sensitive medical data for such purposes even when patient requests it. Therapists who do comply may jeopardize the protective climate for "privilege." They may alienate their patients if the medical report leads to an adverse finding. If they do so without patient's consent, except under legal duress, they may have placed themselves in jeopardy.

FAMILY MEMBERS' WISH TO KNOW

The most frequent requests for confidential information come from families of patients. Their interest in, concern for, and wish to help the patient are natural and to be expected. In most situations, sharing this information with the family is helpful and acceptable to the patient. There might be some information that the patient does not want to divulge even to the most dedicated member of the family. Physicians have learned that in some families the dedication to each other leaves much to be desired. Professed and superficial dedication may be belied by family behavior. Sensitive information divulged to a parent, child, or spouse has been used destructively against the patients. This requires a clear understanding that a patient truly consents to release information to a family member or specifies what information is to be withheld. Where there is family emotional involvement in a situation requiring treatment of one or more members, whether by a psychiatrist or other physician, it might be well to agree upon a policy about confidentiality at the onset—absolute, conditional, or none. The judgment should always be based on the general principle "Is breaking confidentiality, even with the family, for the patient's interest or destructive to the patient's interest?" (17).

COMPLICATIONS FROM CIVIL RIGHTS OF MINORS

The family relationship in confidential medical-data disclosure has always been complicated when the medical information is about minor children. The right of parents to this information has been eroded by developments of relatively recent origin. The erosion is partly due to growing awareness that children also have civil rights independent of parents. This is crucial when children avoid seeking needed medical help because they fear parental discovery and its consequence (18). Children have been known to commit suicide when faced with the dilemma. Recent legislative trends have permitted physicians to treat minors without parental consent. This has been legalized in forty states (18) and supported by law-enforcement action in specific instances. Removing the need for parental consent implies the child's right to privacy in the matter and the independent right to confidentiality. The need has been legislatively directed at treatment for venereal disease, pregnancy, contraceptive devices, alcohol, and other drug abuses. Those treating children seek wider

application of the civil rights of minors. The physician will see the children for other problems, where violating the child's confidence would disrupt needed treatment or create emotional upheaval in some child or the family.

There is one rule to follow if it becomes important to accept the conditions of confidentiality and the child is so promised. The physician must be sure, and probably should so note, that the child is mature enough to understand the problem faced and to cooperate with treatment, and understands the full meaning and consequences of withholding information from parents. In counseling about the problem, a child might be helped to see that parental knowledge would advance the child's interests and not result in the feared adverse consequences. In borderline cases, with the child's consent, professional consultation might be helpful. Children usually go to a physician already familiar to them or trusted by them. A physician treating a family with children approaching puberty could seek agreement with parents and child that the physician have the consent of the parents to enter such a confidential relationship with the child in the future, if the child so decides at that later time. If the child is present when the agreement is reached, and knows this is available, it can prove to be good preventive medicine.

This extension of confidentiality illustrates another problem. In the first place, such treatment might require public health notification. It may be difficult to explain to the patient, adult or minor, that it is a legal requirement. Guaranteeing that a third party maintain confidentiality has proven to be risky. In the case of a minor, investigation of a communicable disease, and reports of pregnancy and abortion might lead to communication at the home address that will disclose the problem to parents. In making arrangements, this should be borne in mind. The question of preventing extension of the communicable disease to family members is also a problem.

DILEMMAS CREATED BY *TARASOFF* CASE OBLIGATION

Prosenjit Poddar, a student at UC Berkeley, was in psychotherapy on an outpatient basis at Cowell Memorial Hospital of the University of California in 1969. When Poddar began making threats to kill a fellow student, Tatiana Tarasoff, and Poddar's therapist, Dr. Lawrence Moore, believed that the threats constituted a possible danger, the latter asked the campus police to take his patient into custody incident to pursuing the legal machinery for involuntary hospitalization. This request was made on August 20, 1969. At the time Tatiana was in Brazil for a summer-long visit. The police did take him into custody, but released him when they found no sign of abnormality or of dangerousness.

Poddar caused no problems, even though he terminated treatment after his therapist took this step. He even became a roommate of Tatiana's brother. Shortly after Tatiana returned, Poddar did kill her, on October 27, 1969. Tatiana's parents filed suit against all individuals involved, and the Regents of the University of California as their employer, for a wrongful death. The plaintiffs gave four legal grounds in support of their claim. The second was based on the defendant's failure to warn the parents of the danger to Tatiana.

The lower courts dismissed the action without a trial because of legal immunity of the defendants plus the overriding need to maintain confidentiality in psychotherapy. The dismissal was appealed to the California Supreme Court, who reversed the lower court's decision and ordered the case to trial in a decision filed December 23, 1974. The Court stated that psychotherapists have a duty to warn potential victims when they determine that their patient is dangerous. Professional societies joined the defendants in a petition for a rehearing that was granted; the hearing was held May 5, 1975. The basis for the amicus curiae intervention of the professionals was that violating confidentiality under those circumstances would be a major impediment to effective treatment for all patients; and that in approximately 99 times out of a hundred the judgement of dangerousness would be invalid as proven by repeated studies. The Court filed its revised decision July 1, 1976, which did not alter the first decision in its essential feature obligating the warning.

Unfortunately, legal redress for untoward consequences of maintaining confidentiality are usually judged after the fact. This is in contrast to making a predictive judgment about breaching confidentiality, with its possibilities or probabilities, as the dilemma first presents itself. The ramifications of a California Supreme Court decision of potential hazard to a third party goes far beyond psychiatric treatment problems as indicated by the amicus curiae briefs in the petitions for, and subsequent rehearing in the *Tarasoff* case (19). The final decision destroyed an important element in protecting confidentiality. It changed the medical ethics (2) and legislative intent (20) from "no privilege" or "may disclose" to "must disclose," when the physician foresees a potential hazard to a third party. "The duty to warn" in that decision (19) ignores the difference between foreseeing a potential hazard and foreseeing an actual culminated destructive act.² In the field of psychotherapy the decision also fails to differentiate between the predictability of a psychogenic source of hazard that depends on a future unforeseeable external circumstance for triggering actual damage and a biologic source of hazard that is present in an infected patient and only requires physical transmission to create the actual damage. The decision also overlooks the realities of prevention in the two. Relevant to the duty to warn the potential victim encompassed by the decision, it can be demonstrated that the warning offers no protection and the court itself documents that it may increase the hazard. In cases of venereal infection in an adult or a minor, avoidance of contact is all that is necessary until current treatment rapidly renders the disease noncommunicable. In the view of the court, withholding of information from the parents can in some cases, after the fact, be alleged to have created emotional distress that a jury might later consider actionable damage. In terms analogous to the *Tarasoff* decision, should the physician refuse the child's request for confidentiality and disclose the information to parents, the possible damage of the child's suicide must be considered. An after-the-fact evaluation might again leave the physician in an actionable position.

²It is good medical practice to break confidentiality if a hazard to society demands it. The decision overlooks the fact that the greatest protection is the indicated treatment. Where this is failing, the California legislature determined, after extensive investigation, that due process for the therapist is as spelled out in the Lanterman-Petris-Short Act (21).

COMPUTERS COMPOUND THE PROBLEM

All the threats or fears of mishandled information have been compounded by the growing use of computers for depositing, storing, and retrieving information. The villain is not computer science, because its developments have contributed greatly to all sectors where information is important. This is true for medical science in all its branches, including treatment. The problem is too-ready access to the information with inadequate controls and anonymity for those tapping into the computer for confidential data. The ease of storing, transferring, and retrieving information has proliferated a demand for access to all information, including confidential medical information, for various purposes ranging from medical research to private industry wishes to governmental programs. Some of these demands have little to do with the medical welfare of the patients or society. In some cases the information is gathered secretly and used against the interests of the patient (22). They document the tie-in of such data from site of origin to local, county, state, regional, and national data banks.

That these concerns are not limited to psychiatric practice, or even just to the United States, is attested by the World Medical Association. Their annual two-day scientific program in Munich, Germany in October, 1973 was devoted exclusively to this problem. Speakers from all over the world discussed various facets of the problem. At least two nations with reputations of liberal orientation openly use identifiable medical data in their computer banks for all kinds of governmental purposes. The only delegates who thought this proper came from iron-curtain countries, and from public health officials of newly evolving countries trying to establish improved mass-delivered health services.

CONFIDENTIALITY AND MEDICAL RESEARCH

A recurrent theme during that conference is constantly at the surface of controversy in the United States. A large segment of researchers indicate that any restriction of access to data-subject identifiable medical information will interfere with needed research. They support, and some even demand, that all data generated at treatment sites be gathered in regional and national data banks (22d). This is the position taken by a research organization headed allegedly by John Baldwin in Oxford, England, operating the Oxford University Record Linkage System (according to several medical sources interviewed in London in October, 1975). The Task Force at the 1976 Key Biscayne Conference on Confidentiality of Health Records independently recommended controlled procedures (23), followed by the Medical Research Council, based at the University College Hospital Medical School, London, England (visited October, 1975). A variation used at St. Patrick's Hospital in Dublin, Ireland by R. J. Draper demonstrated the feasibility of using independent code numbers kept at the treatment site, with follow-up via treatment site, where identifying data is kept separately. The researcher is thus blocked from having or needing the identifying data. Those who devise such protective features in their protocol have uniformly expressed doubt that random collection of infinite details will be either manageable or rewarding, even with computer sorting or correlating. Yet the argu-

ment goes on internationally between those who hope that the computer will be the wished-for breakthrough if they feed it enough details and those who base their research on a planned protocol that may indicate some need for data-subject identifiable data.

PATIENTS' ACCESS TO THEIR RECORDS

A new area of complexity is the growing belief that patients—and parents of minors—have a right to all medical records to insure accuracy of historical data, as a check on treatment adequacy and to permit better cooperation in treatment (24, 25). This is already federal law, since the Privacy Act of 1974, P.L. 93-579, does not differentiate between medical data and other data collections of federal agencies. The Federal Education Act of 1974 contained an amendment by Senator Buckley, popularly labelled the "Buckley Amendment," that forced all educational institutions that receive federal grants to make all records available as noted above. The problems created by the inclusion of medical reports led to a second amendment to the law, restricting disclosure of medical records on demand of advanced school students to a physician of data-subject's choice. Schools through high school are still vulnerable. Some school officials have begun to add a warning about this to their requests for medical information from treating physicians of the school child involved. A number of additional bills in Congress and in the California legislature include such a disclosure section. A few include the provision of limiting the disclosure to a physician of the subject's choice.

The disclosure legislation is based on the general proposition that patients will fare better if well informed about the whole medical process involving them. Those who advocate this usually suggest that opposition is for the purpose of hiding poor medical practice (24, 25). They overlook the fact that there is some medical data that is intolerable for some patients and can cause emotional damage. It is not uncommon to find patients blocking and practicing denial about facts that they themselves have disclosed at another time. Sometimes the true state and diagnosis is intolerable and forced disclosure to the patient proves destructive (11). Disclosure can be "forced" when the family insists the patient get a copy of the record. It is "forced" when the patient wants to "prove" that the condition is other than suggested by partial knowledge that must be revealed for other reasons. Such experiences create doubts about the ultimate wisdom of a blanket disclosure of records to all patients. Such records often contain confidential information about parties other than the patient. They, too, need protection of their confidential disclosures. The suggestion of having a physician of the patient's choice monitor the information is but a compromise, to shift the burden of protecting the patients from themselves—a not infrequent need in medical care.

WORLDWIDE ACTIVITY SEEKING SOLUTIONS

There are enough complexities to demonstrate that there can be no simple resolution of "the right of privacy" vs "the right to know." This is reflected in increasing

numbers of conferences on the subject. The World Medical Association Congress of October, 1973 has been mentioned. Most often they lead to generalized resolutions that do not alter the situation, but do lead to exchange of information about conflicting needs. Congressional hearings (22a, b) have been extensive and led to the Privacy Act of 1974. This is limited to Federal records because broader complexities were too great. It did include a provision for a Privacy Protection Study Commission to explore for further legislative relief. This commission has been holding formal hearings all over the country to obtain facts from all segments of society, not overlooking the problem of protecting medical records per se. The National Bureau of Standards authorized a project to study the role of computers and needs for protecting medical records. This study, directed by Alan F. Westin, is in the process of being reported after two years of detailed study and consultation. Earlier studies were commissioned by the Secretary of Health, Education, and Welfare (HEW), (22b) and the National Academy of Science (22c). They had a profound effect on the content of the Privacy Act of 1974. Confirming the fact that the concern is worldwide is the reference to similar studies in other countries in the bibliography of Ware's HEW report and in Westin's study.

ROLE OF MEDICAL ORGANIZATIONS

Organized medicine has also become concerned. The California Medical Association took the lead in calling attention to the problem in 1970 and trying to mobilize the American Medical Association (AMA) to take definitive action for protecting the rights of patients. As a result the AMA House of Delegates supported and recommended action for the protection of confidentiality in a great number of resolutions from 1972 through 1976. However, the positive achievement has been repeated formulation of a model state law. Another such model, considered by some to have basic flaws due to the complexity of its global approach, was approved at the 1976 annual meeting. However, when the AMA Council on Medical Services reviewed a standard insurance claim form in March, 1973, they did not respond favorably to recommendations that the AMA withdraw approval of the unlimited authorization for release of medical information. Persuaded by the insurance industry representatives to accept a reworded form of equal legal comprehensiveness, the current form, approved by the House of Delegates in 1973, contains this authorization with the imprinted approval of the AMA.³

When the House of Representatives was considering a new Federal Code of Evidence, containing Rule 504, extending privilege to the psychotherapeutic medical data and communications between all physicians and their patients, the former Executive Vice President of the AMA, Ernest R. Howard, wrote Congressman Rodino January 31, 1973, opposing Rule 504 and wanting a physician-patient

³At a Federal Trade Commission quasi-judicial hearing in San Francisco on February 4, 1976, attorneys for Retail Corporation (Equifax) used this to prove that the AMA approved of the practices of the insurance industry and the Retail Credit Corporation in their wide collecting of medical records and information.

privilege that is legally meaningless, as discussed above. He wrote a similar letter to Congressman Hungate on August 1, 1973. On August 26, 1974, after the CMA and AMA House of Delegates protest, Dr. Howard retracted opposition to Rule 504, but by then the damage was done. We now have no federal privilege protection for medical matter. We are reduced to state codes of meaningless physician-patient privilege in 32 states; psychotherapist-patient privilege restricted to psychiatrists and psychologists in seven states; and none for other physicians in their psychotherapeutic dealings with their patients.

The American Psychiatric Association (APA) became alerted to the problem in 1970. Its Task Force foresaw the greater hazards in National Health Insurance, since all proposed legislation gave no attention to the medical-record protection that would be needed. The APA proposed this need in 1972 (26). The recognition that it is more than a physician's problem led to the recommendation that the public and other professionals work together to seek solutions for problems resulting from the conflicting interests. This resulted in the Key Biscayne Conference alluded to above (22d, 23), attended by representatives from over fifty national organizations—medical, legal, educational, religious, consumer groups, computer experts, the press, the insurance industry, and the government, including the military (27). The conference strongly supported the foundation of a private multi-discipline organization to keep abreast of the developing problems and efforts to deal with them. The results of the Key Biscayne Conference led to the recognition that there should be an ongoing dialogue, kept current, between conflicting viewpoints if constructive compromises are to be achieved. This National Commission on the Confidentiality of Health Records was incorporated early in 1976 with 17 national organizations as charter members. Although the AMA participated in all the planning meetings for the Key Biscayne Conference and participated in that conference, again it did not follow up on the resolutions of activity for confidentiality, electing not to join in the National Commission.⁴

The current ferment suggests that there will be much change in the future for medical records and their confidentiality. Consumer concern is reflected in the multiple studies that have legislative goals. It will affect record keeping in hospitals, clinics, and physicians' offices. Teaching and research, as well as treatment, will be affected. It will certainly affect the welfare of patients and, thereby, medical practice. The role of physicians in this ferment and its consequences is unclear beyond their majority affirmation, "I am in favor of confidentiality." Solutions will not be as simple as those for the problems faced by the Hippocratic group.

⁴Correspondence with James A. Sammons, AMA Executive Vice President, failed to elicit the reasons, but other sources indicated that the AMA wished to maintain an "independent stand." There does not seem to be any recognition of the growing dissatisfaction of patients with the current situation.

Literature Cited

1. Edelstein, L. 1943. The Hippocratic Oath. *Bull. Hist. Med.*, ed. H. E. Sigeret, 7:Suppl. 1. Baltimore: Johns Hopkins Press. 64 pp.
2. Pearson, H. L. Jr. 1958. AMA Principles of Medical Ethics. *J. Am. Med. Assoc.*, Spec. ed., Sect. 9, p. 49. 59 pp.
- 3a. Wigmore, J. H. 1961. *Evidence in Trials at Common Law*, 8: Sect. 2380, p. 818. Boston: Little, Brown. 10 vol. Revised ed.
- 3b. Slovenko, R. 1973. *Psychiatry and Law*, p. 62. Boston: Little, Brown. 726 pp.
4. Watson, A. S. 1960. *Confidentiality and Privileged Communication in the Practice of Psychiatry*, Rep. No. 45, pp. 88-113. New York: Group Adv. Psychiatry. Revised ed.
- 5a. Committee on Rules of Practice and Procedure, Judicial Conference of the U.S. 1969. *Preliminary Draft of Proposed Rules of Evidence for the U.S. District Courts and Magistrates*, footnote. Rule 504, p. 53
- 5b. Slovenko, R. see Ref. 3b, pp. 62-63
- 6a. Wigmore, J. H. 1961. see Ref. 3a, Sect. 2285, p. 527
- 6b. Grossman, M., Barchas, J., Johnson, R. G., Satten, J. 1975. Confidentiality and third parties. In *Task Force Report* 9, p. 44. Washington DC: Am. Psychiatr. Assoc. 59 pp.
- 7a. *In re Lifschutz*. 1970. 2Cal3d at 430, 467P.2d at 566, 85 Cal Rptr. at 838
- 7b. *California Code of Evidence*. 1966. Section 912, p. 491. St. Paul, Minn: West
- 7c. Louisell, D. W., Sinclair, K. Jr. 1971. The Supreme Court of California 1969-1970. *Calif. Law Rev.* 59:41
8. Grossman, M. 1971. Insurance reports as a threat to confidentiality. *Am. J. Psychiatry* 128:64-68
9. Porter, S. 1976. Mail order insurance pitfalls. *San Francisco Chron.*, p. 50 (May 3)
10. Tooley, D. 1976. Testimony of Federal Privacy Protection Study Commission. *Los Angeles Times*. Pt. II, p. 1 (June 12)
11. Grossman, M. See Ref. 6, Append. H, p. 53
12. Testimony before Federal Privacy Protection Study Commission, Los Angeles, June 11, 1976
13. Grossman, M. 1975. See Ref. 6 Append. B, pp. 14-20
- 14a. *In re Lifschutz*. 1970. 2Cal3d at 431-32, 467 P.2d at 567, 85Cal. Rptr. at 839
- 14b. Committee on Rules of Practice & Procedures 1969. See Ref. 5a
- 14c. Louisell, D. W., Sinclair, K. Jr. 1971. See Ref. 7c, p. 42
15. Grossman, M. 1975. The psychiatrist and the subpoena. *Bull. Am. Acad. Psychiatry Law* 1:245-54
16. Solomon, P., Kleeman, S. T., Curran, W. J. 1971. Confidentiality in psychiatric screening for security clearance. *Am. J. Psychiatry*. 127:1566-68
- 17a. Grossman, M., Satten, J. 1975. See Ref. 6, Append. F, p. 34
- 17b. Satten, J. et al 1970. *The Field of Family Therapy*, Rep. No. 78. New York: Group Adv. Psychiatry
- 18a. Slovenko, R. 1973. See Ref. 3b, p. 500
- 18b. Peer, I. N. 1976. Confidentiality and consent in psychiatric treatment of minors. *J. Leg. Med.* 4:12-16
- 18c. Modlin, H. C. 1976. The discharged mental patient in the community. *Psychiatry Dig.* 37:16-21
19. *Tarasoff v. Regents of the Univ. of Calif.* 118 Cal. Rptr. 129 (1974) Also S.F.23042, Super. Ct. 405694 (rehearing) July 1, 1976
20. California Code of Evidence. 1966. See Ref. 7b, Sect. 1024, p. 630
21. Petris, N. C. 1972. *The Dilemma of Mental Commitments in California*, p. 143. Sacramento: Calif. Legislature Assem. 204 pp.
- 22a. Ervin, S. J. Jr. 1974. *Protecting Individual Privacy in Federal Gathering, Use, and Disclosure of Information*. Rep. Comm. Gov. Oper., US Senate, accompanying S. 3418, 93rd Congr., 2nd Sess. Washington DC: GPO
- 22b. Ware, W. 1973. *Records, Computers and the Rights of Citizens*. Dept. HEW Publ. No. (OS) 73-97 xi. 346 pp. Washington DC: GPO
- 22c. Westin, A. F., Baker, M. A. 1972. *Data Banks in A Free Society*. Natl. Acad. Sci. New York: Quadrangle. 522 pp.
- 22d. Participants. 1974. Conf. Confidentiality of Health Rec., Key Biscayne, Fla., Nov. 6-9.
23. Spingarn, N. D. 1975. *Confidentiality*, pp. 17-18. Washington DC: Am. Psychiatr. Assoc. 58 pp.
24. Spingarn, N. D. See Ref. 23, p. 14
25. Weed, L. L. 1974. The public needs must be met. *Prism* 2:22-26
26. Grossman, M. 1975. See Ref. 6, Append. C, p. 20; Append. F, p. 35
27. Spingarn, N. D. See Ref. 23, pp. 43-52

**B. LETTER FROM A. EDWARD DOUDERA, EXECUTIVE DIRECTOR,
AMERICAN SOCIETY OF LAW & MEDICINE, SUBMITTING REPORT ON
PRIVACY OF MEDICAL RECORDS LEGISLATION**



AMERICAN SOCIETY OF LAW & MEDICINE

June 21, 1979

OFFICERS

Elliot L. Sagall, M.D.
President
John A. Norris, J.D., M.B.A.
First Vice President
Nelson Schrieber, M.D.
Vice President
Aubrey Milgram, M.B.B.Ch., M.R.C.P., D.C.H.
Secretary
Barry C. Reed, LL.B.
Treasurer
J. Robertson Knowles, M.D.
Honorary Secretary/Treasurer

MEMBERS OF THE COUNCIL

MEDICINE
Donald B. Raskan, M.D., F.A.C.P.
Howard A. Frank, M.D.
Joseph J. Lasker, M.D., M.P.H.
Irving Klein, M.D.
Robert B. Moore, M.D.
Hilary Varguez Milan, M.D.
Irving Kuhl, M.D.
Aron B. Binswiler, M.D.
Richard E. Weber, M.D.
Gerald F. Winkler, M.D.

LAW

Thomas N. Bodner, J.D.
Thomas E. Catgill, LL.B.
Neil E. Chert, J.D.
Lee J. Dunn, Jr., J.D., LL.M.
Bernard D. Hush, J.D.
August B. Hurdle, LL.M.
Paul H. Kheringfeld, LL.B.
Lawrence L. Smith, J.D.
Robert L. Strudel, J.D.
Stephen M. Wenter, J.D.

NURSING

Muriel Acobson, R.N., Ph.D.
Mary M. Goshing, R.N., J.D.
Jane Greenlaw, R.N., J.D.
Ann Peterson Hyde
Frances A. Maize-Kahn, R.N.

PHYSICIANS

Paul Goldhaber, J.D., D.S.
Arthur Goldhamer, D.M.D.
John W. Nemer, D.D.S., J.D.

EDUCATION

George J. Arnes, J.D., M.P.H.
Harold E. Burch, M.D., J.D.
Richard G. Huber, J.D., LL.M.
Fanny H. Miller, J.D.
Arthur J. Southwick, J.D.

OTHER HEALTH CARE PROVIDERS

Thomas N. Dunlap, M.D.
James F. Heller, J.D.
John F. Knight
Maureen E. Kaplan, M.D.
Beatrice Phillips-Nelson, M.N.W., A.C.N.W.

THE LARY

Honorable Kathleen Ryan-Dacey
Honorable Sylvia E. Haxton
Honorable Robert I. Hermann
Honorable John S. Kruttschnitt
Honorable Max Rosen

INSTRUMENTAL

Michael Bevell
Joseph D. Longman
George P. Nasser
John Lakon Thompson, J.D.
David Z. Weisner, LL.B., M.B.A.

ALLEGED

Herbert B. Brant, LL.B.
Paul J. Conner, M.D., J.D.
William J. Curran, LL.M., M.M. Hug
Harry W. Dahl
Douglas Danner, J.D.
Richard E. Gibbs, M.D., J.D.
Kent Hall, J.D.
Kevin M. Schiller, M.D., J.D.
Margaret W. Shaw, M.D., J.D.

GENERAL COUNSEL

Douglas Danner, J.D.
EXECUTIVE DIRECTOR
A. Edward Doudera, J.D.

HONORARY MEMBERS

Donald Cooper, M.D., Ph.D.
William J. Curran, LL.M., M.M. Hug
Honorable John J. Brennan
Honorable Jacob S. Lurie
Honorable Walter H. W. Longblin
Honorable Paul G. Rogers
J. Douglas Shaw, J.D., LL.D.
Carl H. Wachs, M.D., J.D.

Honorable Richardson Preyer, Chairman
Government Information and Individual Rights
Subcommittee of the Committee
on Government Operations
House of Representatives
Washington, D.C. 20515

Honorable Abraham Ribicoff
Honorable Jacob K. Javits
Committee on Governmental Affairs
United States Senate
Washington, D.C. 20510

Dear Senators and Congressman:

In response to your letters of May 2, 1979 and June 6, 1979, respectively, addressed to Elliot L. Sagall, M.D., President of the American Society of Law & Medicine, it is my pleasure to enclose the report of the Society's *ad hoc* Legislative Response Committee which was formed in response to your letters. A list of the persons comprising this committee is attached to the report.

The report concerns H.R. 2979, H.R. 3444, S. 503, and S. 865, all of which address the problems of medical record confidentiality, access, and disclosure. The report was prepared from the combined comments of the members of the Legislative Response Committee and from the tabulation of a questionnaire sent each committee member together with copies of the bills. Since the committee was formed following receipt of Mr. Preyer's letter, the report concentrates upon the two House of Representatives bills. Comments are made upon such issues as patient access to their records, correction or amendment, consent to disclosure, unconsented-to disclosures, research use, and sanctions. The report summary suggests another approach federal legislation might also follow.

Since this is the first such report made by the American Society of Law & Medicine in response to Congressional inquiries, I would greatly appreciate your comments and

NATIONAL HEADQUARTERS
520 COMMONWEALTH AVENUE, SUITE 211
BOSTON, MASSACHUSETTS 02215
TELEPHONE: (617) 262-4990

"Continuing Medical Education"

those of the House and Senate Committee staff on the report and how its utility could be improved.

I trust you will provide each of the members of your committees with a copy of this report, and I appreciate the opportunity to assist you in your deliberations upon this important medicolegal issue.

Sincerely,



A. Edward Doudera, Esq.
Executive Director

AED/jet

Enclosures

cc: Elliot L. Sagall, M.D.
John A. Norris, J.D., M.B.A.
Sidney Scherlis, M.D.
Aubrey Milunsky, M.D.
Barry C. Reed, J.D.
Senator Edward Kennedy
Senator Paul Tsongas
Congressman Thomas P. O'Neil, Jr.
Congressman John J. Moakley
Members of the ad hoc Legislative Response Committee

AMERICAN SOCIETY OF LAW & MEDICINE
ad hoc LEGISLATIVE RESPONSE COMMITTEE

Patient Access to Their Records

1. On the question of whether federal legislation to guarantee citizens the right of access to the information contained in their own medical records was desirable or appropriate at this time, seven of the ten members voted in the affirmative. The three dissenters did not disagree at all with the principle but felt that state action would be a more appropriate response,¹ and one, a trial practitioner, specifically questioned the need for a federal umbrella over the review and control of medical records. The statutory recognition of an individual's constitutional right of privacy in his or her own medical information and history, as set forth in H.R. 2979 §2(a), is also essential to effective legislation.

An attorney who has written extensively on the legal aspects of medical records, and who approved of federal legislation at this time, feared, however, that statutory provisions such as those contained in H.R. 2979 and H.R. 3444 would make the problems of medical record confidentiality and disclosure more complex, and perhaps, too complicated for layperson medical record librarians to interpret. This would result in unnecessary legal problems and bad public relations for the health care facility.

It was suggested by another member that the medical care facilities' obligation to accord an individual access to his or her own medical information, see H.R. 3444 §101(a) and H.R. 2979 §111(a)(1), should not arise until the patient has been discharged from the facility since medically it may not be in the patient's interest to "monitor his own chart while he is in the hospital."² Further, a provision similar to H.R. 2979 §111(a)(2),

AMERICAN SOCIETY OF LAW & MEDICINE
ad hoc LEGISLATIVE RESPONSE COMMITTEE
June 21, 1979

which permits a health care facility to require that the request for an inspection be made in writing, seems advisable, and, in fact, should be considered as a statutory requirement in order to prevent fraudulent access.

One member expressed the need to clarify the definition of "medical record" (see H.R. 2979 §101(10)) and suggested that consideration be given to the idea utilized in Ontario, Canada, wherein the record is defined to include only what a health care facility or medical care provider actually prepared and not what it has received from other health care providers.

2. Three members thought that access to one's own medical record should be available on an absolute basis, although one favored an exception for psychiatric records and statements made by others about persons other than the patient. For example: Patient's mother tells physician that patient's real father is not her husband and patient is unaware of this fact.

The other members of the committee essentially favored the idea of letting the health care facility responsible for maintaining the record refuse access if it reasonably concluded that disclosure "would be likely to be harmful to the individual or to another person" (H.R. 3444). The idea of an independent tribunal or review board making such decisions was not endorsed by any of the members.

One member suggested that only the attending physician should have the power to refuse a patient access, and then only for a medical reason, including psychiatric problems. Another member emphasized that any determination of "harm" must be made by a physician, and not by medical record librarians or hospital administrators. Such an approach would avoid the need to exempt all psychiatric records from an individual's right to access. For instance, in Canada, all documents and records relative

AMERICAN SOCIETY OF LAW & MEDICINE
ad hoc LEGISLATIVE RESPONSE COMMITTEE
June 21, 1979

to committal in a mental institution are available to a patient or his attorney.

An attorney on the committee perceived the loose language of H.R. 3444 § 101(b) at lines 16 to 18 (health care facility determines if harm will result) as creating a license for health care providers to thwart or hinder attorneys who are evaluating cases for potential malpractice. Another member endorsed strongly the requirement of H.R. 3444 that the unsupplied information be privately communicated to a specific designated person in the patient's behalf. Such a requirement could co-exist nicely with a provision granting access except upon a finding of medical harm by the attending physician.

Should Congress decide not to invoke a requirement for a medical basis for denying an individual access to his or her own medical record, a requirement that the Secretary of H.E.W. publish within a specific period of time guidelines relative to "likelihood to cause harm," as utilized in H.R. 2979 §111(c) is essential.

3. There was concern on the part of many members of the committee that any legislation on this issue should concentrate more specifically upon its impact upon other statutes concerning medical records, especially those involved with alcohol or drug abusers, incompetents, and minors.

One member, who is legal counsel to a major medical center, suggested that the specific concerns of minors were inadequately addressed. In her opinion, minors of 14-15 or over should have a right of privacy in their medical records relative to parental access and should be able to sign releases without parental knowledge. In her opinion, H.R. 2979 §103(a) would give parents of persons under the age of 18 an implied right to the

AMERICAN SOCIETY OF LAW & MEDICINE
ad hoc LEGISLATIVE RESPONSE COMMITTEE
June 21, 1979

same right of inspection an adult patient would have of his or her own record. The mature minor rule, which allows a minor's consent to medical treatment if certain criterion are met, was mentioned as one problem such a policy would face.

Correction and Amendment

4. All but two of the members favored the idea that any federal legislation state a specific method by which an individual could challenge and correct erroneous information in his or her own medical record.³ One dissenter expressed the opinion that such a procedure was simply too complicated for laypersons to utilize. Of those expressing a preference, H.R. 2979 was preferred 3 to 1 as the procedure to be utilized.

One attorney member suggested that notations in a medical record should never be rewritten or "corrected." Errors should be lined through, a new entry written or attached, and the date recorded as well as the initials of the physician making the change. If not for medical reasons, erasures and obliteration of entries should be minimized in order to avoid allegations of impropriety.

If the patient disagrees with a statement, and the health care facility refuses to make the requested change, he or she should be given the opportunity of inserting a statement upon the chart which asserts his or her own views.

5. All but two of the committee members favored the requirement that health care facilities be required to see that such revised or amended information is incorporated into the copies of medical records previously supplied to third parties. To this end, it seems advisable to require that those persons responsible for the custody of medical

AMERICAN SOCIETY OF LAW & MEDICINE
ad hoc LEGISLATIVE RESPONSE COMMITTEE
June 21, 1979

records maintain detailed and accurate records on the disclosure of a specific medical record, whether consented to or not. In H.R. 3444 §102(b), the patient's right to have inaccurate, incomplete, or disputed information communicated to third party recipients of his or her medical information is made contingent upon the health care facility keeping records. Accurate records of disclosures are essential even if corrections, amendments, or statements of disagreement are not to be communicated to third parties who received the erroneous medical information previously.

One dissenter felt that such a requirement would unduly complicate the record and would involve too much paperwork. The other dissenter thought it unnecessary to communicate the post-disclosure revision unless it related to the specific third party. This position was also expressed by an attorney who favored the notification requirement. Such a provision, however, would require the health care facility to make a determination, presumably upon the criterion of pre-established guidelines, that the information would or would not be of interest to the third party.

It would seem that a requirement that revised or amended notations in a medical record be communicated to all prior recipients of the information would generally be favored. Such a policy is advisable considering the wide range of significant determinations, both medical, social, and economic, that are made by various governmental agencies, private insurers, and others who have or can obtain access to an individual's medical record. Considering the many uses to which an individual medical record can legally be put, permitting information known to be inaccurate, incomplete, or in dispute to remain uncorrected seem to deny the right supposedly being affirmed.

AMERICAN SOCIETY OF LAW & MEDICINE
 ad hoc LEGISLATIVE RESPONSE COMMITTEE
 June 21, 1979

Consent to Disclosure

One member of the committee expressed concern with the meaning and scope of "consent" in the context of medical record information. Must consents to disclosure be specific for each instance and be included within the medical record, or can a patient consent, via contract or expressly, to the blanket disclosure of his entire medical record? Legally, how valid is a consent to release yet to be accumulated information, the scope and significance of which is unknown? In addition to clarifying such questions, any federal legislation should require that patients or medical insureds be informed of any rights they may be waiving by accepting the medical insurance benefits or requesting health care services.

Un-consented-to Disclosures

6. There was considerable agreement amongst the committee members that any such legislation should detail specifically each and every instance in which disclosure of an individual's medical record to a third party could legally occur without the individual's consent. Concomitant with such authorization, a duty should be imposed upon the health care facility or medical care provider to disclose only in proper situations, or those reasonably believed to be proper, and to notify the individual whose record was disclosed of the disclosure unless a court orders otherwise.

One committee member was aghast at the lack of restrictions placed upon governmental access to medical records evidenced in both H.R. 2979 and H.R. 3444. In her opinion, except for audit and payment purposes, the government, and especially law enforcement agencies, should have no greater right of access to an individual's medical chart as would that individual's next-door neighbor. Another attorney member of the

AMERICAN SOCIETY OF LAW & MEDICINE
ad hoc LEGISLATIVE RESPONSE COMMITTEE
 June 21, 1979

committee also thought that the exceptions afforded governmental agencies such as the Secret Service or FBI were too broad, and that, at a minimum, a court-issued subpoena should be required for all un-consented-to disclosures of medical information to governmental agencies.

Relative to the "Conditions for Disclosure of Medical Information" in H.R. 3444 §105, two attorney members expressed concern with the vague language of §105(b)(3): one with the undefined and often varying term "accepted medical practice," and the other with the phrase "next of kin or persons with whom the individual has a personal relationship." One attorney, who is accustomed to ready access to medical information because of liberal state statutes and practice, suggested that legislative standards like "accepted medical practice" or "compelling circumstances" are too subjective and would provide an avenue whereby a health care facility could block an inquiry into a bad or potentially bad situation.

7. On the question of whether federal legislation should permit "routine" disclosures of admission data and general medical condition reports by the health care facility, only four committee members voted affirmatively.⁴ Three members considered H.R. 3444 §105(b)(10) to be inappropriate. In clause A of §105(b)(10), release of minimal routine medical reports is permitted if the "individual has not objected to the disclosure."

If the health care facility was assumed to possess the authorization to make known the "presence of the individual at the facility at a particular time," or what services had been provided to the individual, or "his general medical condition" (H.R. 3444 §105(b)(10)), a strong

AMERICAN SOCIETY OF LAW & MEDICINE
ad hoc LEGISLATIVE RESPONSE COMMITTEE
June 21, 1979

majority of the committee favored a requirement that the health care facility be required to advise patients of this and other un-consented-to disclosures of medical record information it thought itself entitled to make under law.

Research Use

8. A majority of the committee favored requiring that the legislation specify the conditions under which medical records may be utilized in research projects by non-attending physicians and other researchers. The strength of the majority decreased when the committee was asked whether the recommendations of the United States Privacy Protection Study Commission should be adopted in regard to retrospective research use of medical information; the most cited reason being that they were too vague.

One member suggested that all identifying information be removed from records used in research, unless essential to the project. The local institutional review boards created under the National Research Act and regulated by the Food and Drug Administration were suggested as suitable and appropriate decision-makers in this regard.

Sanctions

9. On the question of sanctions for violators of the proposed legislation, all but one member of the committee favored the imposition of civil penalties upon the violator and the person and/or corporate entity which allowed the breach of confidentiality, i.e., the record custodian and the health care facility. A majority also favored criminal penalties for violators, especially those who knowingly request or obtain medical record information from a health care facility under false pretenses or through deception.

AMERICAN SOCIETY OF LAW & MEDICINE
ad hoc LEGISLATIVE RESPONSE COMMITTEE
June 21, 1979

In light of one committee member's concern with the wide range of access provided in both H.R. 2979 and in H.R. 3444 to governmental agencies and to law enforcement officials in particular, it seems reasonable to impose some sort of sanction upon the intentional, unauthorized, and inappropriate use of individual medical record information by individuals operating on behalf of the governmental agency granted privileged access to the information. One member also suggested that specific attention be paid to persons or institutions who release or subsequently misuse medical information they have obtained through a valid authorization.

Summary

In general, while the overall thrust of the legislation was favored, most of the committee disagreed with some of the significant aspects of the two bills and the value of these specific bills was questioned. Concern was especially evidenced in regards to the numerous exceptions to the prohibition against un-consented-to access and the real diluting effect such statutory provisions have upon the right of privacy supposedly being affirmed by the legislation. It was also noted that the public is generally unaware of all the potential breaches of confidentiality and improper uses of their personal medical data that are possible, and that protective legislation is required.

The medical record educator on the committee commented that no concern was being given to those individuals who function in the medical records department. The need for specified qualifications for such personnel, and for the training of individuals who would be held liable for the improper release of medical information was emphasized. It was also suggested that more specific and definitive definitions are required since

AMERICAN SOCIETY OF LAW & MEDICINE
ad hoc LEGISLATIVE RESPONSE COMMITTEE
June 21, 1979

many of the terms are presently open to very subjective interpretation. Most significantly, the language of H.R. 3444 §105(b)(1-22) is so open to subjective interpretation that the medical records custodians, who are going to be subjected to at least civil, and maybe criminal, penalties, will be forced into making decisions inappropriate to their training and expertise. Such problems warrant investigation of another approach.

The idea was suggested that a statutory guarantee of privacy and confidentiality be created in one's personal medical information as recorded and maintained by a health care facility as then defined by the legislation. This would confirm a recommendation of the U.S. Privacy Protection Study Commission and such recognition would enforce the idea that the protection of the privacy of patient medical information is essential to quality care and to establishing a true professional relationship between health care provider and patient. Such a provision would, of course, provide individuals with a right of access to their own information. Only where an attending physician determines that in his medical opinion the information sought by the individual would be harmful to him or herself, should disclosure be denied.

The right of privacy in one's own medical information would then require health care facilities in custody of such records to strictly guard against unauthorized and un-consented-to disclosures. The legislation should not attempt to elaborate all situations when disclosure may arise, but rather should define and specify the conditions and limitations upon disclosure by the health care facility. For example, un-consented-to disclosure is permissible if done for medical reasons or upon receipt of a subpoena. Wherever possible, "access" should only entail use of the specific information required and non-essential information

AMERICAN SOCIETY OF LAW & MEDICINE
ad hoc LEGISLATIVE RESPONSE COMMITTEE
June 21, 1979

should not be disclosed.⁵ Persons or institutions attempting to secure un-consented-to access to the medical information of a specific person should be required to make a written showing of their "need to know" the sought after information. The health care facility, administrator, or his delegated official, would be responsible for reviewing, or establishing a protocol for the review and approval of such requests and would remain responsible for information disclosed on the individual.

In comparison, H.R. 3444, which first affirms a patient's right of privacy and confidentiality in his or her medical information, then proceeds, through nearly 12 pages of exceptions, to erode it. The subjective and often discretionary terms utilized in H.R. 3444 §105(b)(1-22) would be subject to significant and substantial misunderstanding by patients and by those charged with interpreting the regulations, and would result in confusion, misunderstanding, and further abuses, both intentionally and unintentionally, of individual medical information and the right of privacy in such information.

Notes

¹ Individual state action was also the recommendation of the recent Privacy Protection Study Commission; see their final report, chapter 7, Recommendation 2.

² See, e.g., CONNECTICUT GENERAL LAW, c. 50 §4-104

³ Babin, S., Changing Notes in Medical Records: A Proposal, MEDICO-LEGAL NEWS 6(1):4 (Spring 1978).

⁴ See Holzer, J.F., Patient Privacy and the Media, MEDICOLEGAL NEWS 7(1):8 (Spring 1979).

⁵ Confirms Privacy Protection Study Commission recommendation 9, chapter 7 - Record Keeping in the Medical Care Relationship.

AMERICAN SOCIETY OF LAW & MEDICINE
ad hoc LEGISLATIVE RESPONSE COMMITTEE

George J. Annas, J.D., M.P.H.
 Associate Professor of Law & Medicine
 Boston University School of Medicine
 Editor-in-Chief, MEDICOLEGAL NEWS
 Boston, Massachusetts

Frances H. Miller, J.D.
 Associate Professor
 Boston University School of Law
 Boston, Massachusetts

A. Edward Doudera, J.D.
 Executive Director
 American Society of Law & Medicine
 Managing Editor, MEDICOLEGAL NEWS
 Boston, Massachusetts

Richard A. Ott
 Director of Publications
 Medical Legal and Mental Health
 Illinois State Medical Society
 Chicago, Illinois

Helen T. Epstein, R.R.A.
 Director, Medical Record Administration
 The University of Tulsa
 Tulsa, Oklahoma

Ace Pickens, J.D.
 Brown, Maroney, Rose, Baker
 & Barber
 Austin, Texas

Emanuel Hayt, J.D.
 Hayt, Hayt, & Landau
 Great Neck, New York

John A. Robertson, J.D.
 Associate Professor
 University of Wisconsin Medical School
 and Legal School
 Madison, Wisconsin

Angela R. Holder, J.D.
 Legal Counsel
 Yale-New Haven Medical Center
 New Haven, Connecticut

Gilbert S. Sharpe, LL.B., LL.M.
 Legal Counsel
 Ministry of Health
 Toronto, Ontario, Canada

James F. Holzer, J.D.
 Assistant Administrator
 Massachusetts Eye & Ear Infirmary
 Boston, Massachusetts

Robert C. Strodel, J.D.
 Strodel & Kingery, Associates
 Peoria, Illinois

Historical Note

Derivation:

1930 Rev. § 191.
1929 P.A. ch. 277.

Cross References

Uniform system, municipalities, see § 7 399.

Library References

Hospitals \Leftrightarrow 3.

C.J.S. Hospitals § 5.

§ 4-104. Inspection and subpoena of hospital records

Each private hospital, public hospital society or corporation receiving state aid shall, upon the demand of any patient who has been treated in such hospital and after his discharge therefrom, permit such patient or his physician or authorized attorney to examine the hospital record, including the history, bedside notes, charts, pictures and plates kept in connection with the treatment of such patient, and permit copies of such history, bedside notes and charts to be made by such patient, his physician or authorized attorney. If any such hospital, society or corporation is served with a subpoena issued by competent authority directing the production of such hospital record in connection with any proceedings in any court, the hospital, society or corporation upon which such subpoena is served may, except where such record pertains to a mentally ill patient, deliver such record or at its option a copy thereof to the clerk of such court. Such clerk shall give a receipt for the same, shall be responsible for the safekeeping thereof, shall not permit the same to be removed from the premises of the court and shall notify the hospital to call for the same when it is no longer needed for use in court. Any such record or copy so delivered to such clerk shall be sealed in an envelope which shall indicate the name of the patient, the name of the attorney subpoenaing the same and the title of the case referred to in the subpoena. No such record or copy shall be open to inspection by any person except upon the order of a judge of the court concerned, and any such record or copy shall at all times be subject to the order of such judge. Any and all parts of any such record or copy, if not otherwise inadmissible, shall be admitted in evidence without any preliminary testimony, if there is attached thereto the certification in affidavit form of the person in charge of the rec-

§ 4-104

STATE AGENCIES

Title 4

ord room of the hospital or his authorized assistant indicating that such record or copy is the original record or a copy thereof, made in the regular course of the business of the hospital, and that it was the regular course of such business to make such record at the time of the transactions, occurrences or events recorded therein or within a reasonable time thereafter. A subpoena directing production of such hospital record shall be served not less than twenty-four hours before the time for production, provided such subpoena shall be valid if served less than twenty-four hours before the time of production if written notice of intent to serve such subpoena has been delivered to the person in charge of the record room of such hospital not less than twenty-four hours nor more than two weeks before such time for production.

(1949 Rev., § 294; 1955, Supp. § 111d.)

Historical Note

Derivation:

1930 Rev. § 192.

1927 P.A. ch. 291, § 1.

The Public Act of 1955 added the provisions respecting subpoena of hospital records, service of subpoena,

delivery of records or copies into court clerk's custody, the sealing of records in envelope and inspection thereof, and admissibility in evidence as records kept in regular course of business.

Library References

Hospitals \S 3.

C.J.S. Hospitals § 5.

Notes of Decisions

1. In general

Counsel of record are expected to examine hospital records before trial to ascertain admissibility of all or any part of them in order to avoid delay and confusion in trial. *Janini v. Daily* (1966) 217 A.2d 707, 153 Conn. 415.

Amendment providing that any and all parts of hospital record or copy, if not otherwise inadmissible, shall be admitted in evidence without preliminary testimony if properly certified did not change rules of evidence but only simplified procedure for obtaining hospital records and introducing them, and only such parts of the hospital record as are generally admissible can be introduced. *Id.*

Statement in argument that plaintiff suing for injuries arising out of automobile collision had developed left-sided headache, had passed out at wheel of vehicle, and had nearly been in a collision 16 months after the accident in question did not make hospital record for the plaintiff's hospital admission one year after the accident admissible. *Id.*

In action for injuries, where plaintiff's physician sent plaintiff to a hospital for diagnostic purposes and physician received from hospital a copy of record of plaintiff's case and placed it in his file which he kept as a record in regular course of his business and physician on the witness stand produced file and plaintiff took from it the copy of the record,

Changing Notes in Medical Records: A Proposal

Susan Babin, M.Ed., M.P.H. Cand.

The hospital medical record is a multi-purpose document. It is the repository for all relevant (and sometimes not so relevant) medical information concerning the care and treatment of a patient during his or her stay in the hospital or visits to the Out-Patient Department or Emergency Ward. In addition, it serves as a form of communication among all past, present and future providers to help them provide medical care to the patient. With the gradual disappearance of solo practice as a major mode of health care delivery, and with the emergence of group practices, Health Maintenance Organizations, neighborhood health centers and hospital based primary care programs, this communicative function assumes even more importance. As a legal document, its existence is mandated by statute in many states, and it is frequently used as evidence in malpractice suits and other court proceedings.¹ The medical record also serves as a research resource from which statistics and findings can be compiled to aid in a variety of studies and medical audits. Finally, it is an educational document which often is employed as a teaching tool in training students in the health field.

Although the medical record is supposed to exist for the benefit of the patient as well as the physician,² historically patients have not been afforded unlimited access to their records.³ The recent publicity concerning the Massachusetts statute which grants the patient the right of access to his hospital medical record without having to resort to complicated legal remedies,⁴ and the growing opinion of some members of the medical community that providers should share information contained in the record with the patient as a matter of routine,⁵ could precipitate interesting legal dilemmas.

One problem that arises is the possibility that once a patient sees a notation that contains a disparaging comment, he might want it eliminated or altered. It is generally acknowledged that sometimes the medical record contains derogatory statements which do not bear directly on the medical problem or value judgments by the health care provider which may not be true.⁶ Since, in the past, few patients saw these notes, there was no legal "problem" regardless of what one thinks of the ethics of this practice. In fact, one author implies that the reason physicians are so reluctant to show patients their records is that no legal problems seem to arise when physicians keep the records hidden.⁷ Now, however, with patients in Massachusetts presumably aware of the fact that

they are free to see their hospital records on demand, it is likely that there will be more requests by patients to inspect their medical chart, and the question of altering a note may arise. Consider the following example:

A 45 year old woman comes to the Emergency Unit of a teaching hospital on a Saturday night at 11:00 p.m. presenting complaints of weakness and dizziness. She seems very upset and, although able to give a clear medical history, becomes uncooperative and somewhat incoherent when a social-emotional history is taken by the medical intern. Her breath smells slightly of alcohol, although she claims to have had "only one or two cocktails." The intern decides from her history and general demeanor that she is drunk. After some routine tests which are negative, she is discharged home, with an appointment to the medical clinic for a complete physical examination. Part of the note the intern writes in the chart reads: "Impression: dizziness due to intoxication. ? Alcoholic."

The patient continues to be followed in the medical clinic by various providers for a period of four years, and each time she sees a new provider she is asked about her "drinking problem." After finally developing a good relationship with one provider, she asks to see her record and learns about the original note. She feels the note is unfair and inaccurate. On that particular night, she explains, she had, in fact, had only one drink, she was upset, "uncommunicative, and somewhat incoherent" because she had just learned that her husband had run off with the woman next door, and she was too embarrassed to tell that to the intern. She does not want to be labelled an "alcoholic," even " ? alcoholic", and she asks to have the note in the record changed to reveal the true facts.

Can the hospital legally comply with this request? Can notes in the record be changed after the fact, and, if so, how, and by whom should the correction be made?

The ensuing discussion will only be concerned with notes that are subjective, and will not be concerned with diagnosed medical conditions which a patient does not wish to be recorded (i.e. diabetes, hypertension, etc.), as the latter category raises a different set of questions. Concentration will also be on Massachusetts law. Assuming that a derogatory or incorrect impression has been recorded in the chart, the patient can set forth three arguments for having it changed. 1. an incorrect statement in the chart violates statutory law, 2.

Principal Planner for Ambulatory Care, Office of State Health Planning, Department of Public Health, Commonwealth of Massachusetts. The views expressed in this paper are those of the author and do not necessarily reflect those of the Massachusetts Department of Public Health.

the interest of the patient concerning his or her own medical record supersedes all other interests, and 3) the statement is defamatory.

Statutes and Regulations

Massachusetts requires by statute that each hospital licensed by the Department of Public Health maintain records on all patients, and that these records be kept for thirty years.⁹ State licensing regulations, Joint Commission on Accreditation of Hospitals (JCAH) standards, and Medicare regulations for participating hospitals all state that accurate and complete records must be maintained.¹⁰ In addition, the Medicare regulations require that medical records contain "sufficient information to justify the diagnosis and warrant the treatment and end result" and also state that "the provisional diagnosis is an impression reflecting the examining physician's evaluation of the patient's condition based mainly on physical findings and history."¹⁰ This implies that value judgments and offhand comments not based upon physical findings, for example, a 23 year old "seductive" female or a 16 year old "crazy patient" might be deemed inaccurate and incomplete. For the comment concerning the 23 year old female to be considered accurate, the physician would have to document in the chart a specific history of her having seduced men or specific evidence that she tried to seduce him. The physician might argue that this is a commonly used psychiatric expression indicating that the patient is manipulative or he might argue that his impression that the patient is seductive is important to future psychological assessment. In either case, it should be necessary for him to clearly spell out the basis for the assessment. In the initial example presented any reasonable person would agree that a patient smelling slightly of alcohol and being incoherent on one occasion does not justify an impression of "seductive" based on accurate physical findings and history.

If medical records are to be accurate and complete, notes such as these must be alterable in some way. Potentially standing in the way of this is the fact that Massachusetts law requires that records be kept for thirty years. Does this imply that the inaccurate or incomplete information must also be kept? The law is not explicit on this point, and there have been no cases to support either view. One could argue that the state, as well as the patient, has an interest in hospitals keeping accurate and complete information because records are also used in medical audits for licensing purposes,¹¹ to monitor professional standards, as well as for evidence in malpractice suits. The state might want the note to remain in original form even though inaccurate if the standard of care in an institution were at issue in renewing a hospital's license. Similarly, the patient might want it to remain in original form if he were to sue the hospital. This poses a conflict, for while the regulations imply that only accurate and complete notes should be in the chart, there does not seem to be any medical reason for keeping inaccurate and incomplete notes. The proposed resolution of this conflict lies in the way in which such notes are to be changed.

It would seem then that hospitals have a duty to keep accurate and complete notes, and that there is nothing in the statutes to prohibit them from correcting erroneous notations. But does this mean that the hospital can change all notes that are inaccurate? If this were the case, then notes could be changed whenever an inaccurate diagnosis or impression is recorded and a malpractice suit is subsequently filed. In one case, a physician treated a patient for "mumps and ? pharyngitis" with penicillin, the patient had an anaphylactic reaction to the penicillin and died. The court ruled that a course of penicillin is accepted medical practice for treating pharyngitis,

but not for mumps alone. Since it was determined that "pharyngitis" was added after the patient had died, the doctor was held liable.¹² Here the doctor had changed a note in the record to protect his interests and to avoid liability, not to make the note accurate. If the doctor had thought there was a question of pharyngitis at the time of the examination and had recorded it at that time, he would not have been held liable.

How does one determine what an "accurate and complete" note is? Under the JCAH standards notes must contain sufficient information to justify the diagnosis, and the impression or diagnosis not based upon adequate and complete information is inaccurate. Thus, it would appear that as long as the physician can justify his or her impression by physical findings or history, the note is complete. In our example of the

It would seem then that hospitals have a duty to keep accurate and complete notes, and that there is nothing in the statutes to prohibit them from correcting erroneous notations. . . .

woman labelled " ? alcoholic," if the intern had documented that the history revealed that this same patient had been brought into the Emergency Ward every night for the past two weeks drunk and that the physical findings showed cirrhosis of the liver, then his impression would be "accurate," and the record would be complete according to regulations. Accordingly, the patient would have no grounds to have the note stricken or changed. On the other hand, suppose the physician who has diagnosed a patient as having been an alcoholic wishes to change the note because he realizes the patient is going to sue him. He might claim the same grounds — that he is merely altering information to make it "accurate and complete" — not that he is acting to protect his interests. If we argue that the patient can change a note because of the legal requirements that notes be accurate and complete, cannot the physician and hospital argue that they too should be permitted to change notes?

Clearly the courts do not look favorably on altering records to cover mistakes, nor should they. The Report of the DHEW Secretary's Commission on Medical Malpractice acknowledges that this practice does exist and finds it "intolerable." Further, the report recommends that states enact legislation to "prohibit modification, alteration or destruction of medical records with the intent of misleading or misinforming patients."¹³ It seems significant, however, that the Commission does not recommend never allowing records to be altered, but rather that altering must not be done with an *intent* to mislead or misinform patients. Obviously, how one determines what the hospital's true intent is, remains a difficult problem. One could argue, therefore, that the whole prospect of changing notes is a risky procedure. While this is true, it does not negate the fact that there is nothing in the law to prevent inaccurate notes from being changed.

Interest of the Patient in his Record

Although historically courts have held that the medical record is the property of the hospital or physician,¹⁴ more recent decisions have held that the patient has the right to the information in the record and that the hospital or physician is merely the custodian of the record.¹⁵ In a sense, while the hospital owns the record — the ink and paper on which it is printed — the patient "owns" the information contained in it.¹⁶ If this is so, should not the patient have some control over what goes into the record? Courts have also held that the

interest of the patient in the information contained in the record supersedes any interests of the hospital.¹⁷ Although such cases dealt with the patient's right of access to the information contained in the record, it would presumably follow that the patient's interest in the record would come before the hospital's interests in relation to other issues as well.

What are the patient's and the hospital's interests in the record? By statute, regulation, and custom, the record is generally acknowledged, among other things:

- To serve as a basis for planning patient care. . . .
- To document communication between the responsible practitioner and any other health professional contributing to the patient's care.
- To assist in protecting the legal interest of the patient, the hospital and the responsible practitioner.¹⁸

In this context, misinformation may serve as a detriment to the patient's care, and should therefore, be corrected. A note similar to that cited in the first example could interfere with the care the patient receives as well as the planning for later care.

... misinformation may serve as a detriment to the patient's care. . . .

A future provider could conceivably concentrate on the "drinking problem" and miss other problems that the patient is having because he assumes they are related to the "drinking problem." Although courts have held that physicians have a duty to rely upon their own examinations, rather than on past notes, because of the possibilities of inaccuracies,¹⁹ the realities of the situation are that past notes may color a provider's thinking about the patient and may, in fact, affect the care the patient receives. It would seem, therefore, that if the hospital is attempting to provide good care, then it, too, has an interest in changing the note and removing inaccurate information. As the record serves to protect the legal interests of all the parties, it would appear that the patient might not want the note changed if he plans to use it as evidence of negligence on the part of the doctor. For the hospital to unilaterally change the record would clearly be wrong, as that would amount to covering up a mistake and would injure the patient's interests. With both the hospital and the patient having a legal interest in the note as evidence, both parties should be concerned about having only appropriate notes in the chart. In our hypothetical example, where the hospital changes the note to avoid the lawsuit, one could also argue that since the patient's interest in the note supersedes that of the hospital's, his interests are not being served in this case, as the hospital is covering up information which the patient might have used as evidence.

Defamation

A defamatory statement has been defined as one which "tends to injure reputation in the popular sense, to diminish the esteem, respect, goodwill or confidence in which the plaintiff is held or to excite adverse, derogatory or unpleasant feelings or opinions against him."²⁰ The assertion that one may be an alcoholic would seem to fall into the category of defamation. One could argue that this was only an impression and not a statement of fact. However, for a statement to be defamatory, it must be perceived by a third person as being defamatory and injurious to the reputation of the one defamed.²¹ Arguably, even being labeled as a possible alcoholic could injure one's reputation. Although this might be a

debatable point, other common value judgments in the charts are more obvious, e.g., "crazy patient."

Defamation consists of two concepts — libel and slander, libel being the written form, and slander the verbal.²² In the context of medical records we are concerned with libel. And the question arises, does the patient have a cause of action against the hospital on the basis of a libelous statement occurring in the chart? In order for libel to be actionable, there must be a "false and unprivileged publication in writing which assails the honesty, integrity or virtue of another and thereby exposes him to hatred, contempt or ridicule."²³

Two defenses against a charge of libel are truth and privilege. The first we need discuss only briefly. It remains for the hospital to prove that the defamatory statement was true, for example, that the patient was in fact an alcoholic. In our initial example this would undoubtedly be difficult to prove. One possible defense is that the physician thought the statement to be true and acted innocently. However, it does not appear that the physician availed himself of all possible means to corroborate this statement, and a court has held that when a newspaper published defamatory matter innocently, believing it to be true, the newspaper was still held liable because it did not check out its sources thoroughly enough.²⁴ The same rule would seem to be applicable here.

Privilege deserves further exploration. Whether the statement is privileged or not depends upon the circumstances. If the statement is published for a proper purpose, then a conditional privilege exists.²⁵ "Proper purpose" usually means to protect an interest of anyone who has a reasonable interest in the publication, such as the publisher himself, society in general, or a third person. The fact that those in the hospital having access to the chart, i.e., physicians, nurses, and other personnel, are involved in the care of the patient makes the information in the chart privileged to them because presumably the interest of the patient is being served. Accordingly, one could not say that the hospital is liable for a defamatory statement because a nurse or others in the course of taking care of the patient may see the chart, because in that situation the information would be considered privileged. Further, if the patient consented to the release of the defamatory information, then the hospital could not be held liable. Records might also be considered privileged if they are used for insurance, research, medical audit, or similar purposes, on the ground that a greater social interest is being served. However, these value judgments would not be relevant and therefore the notation in the record would not be privileged.

The question remains, can the patient bring a libel suit against the hospital? It is probable that he or she could not until the information has been published.²⁶ However, it seems that the patient could be justified in requesting that the note be changed on the basis that unprivileged defamatory information exists in the medical record which could fall into the hands of disinterested parties. The hospital, cognizant that a libel suit might result, would be unwise not to comply.

Changing the Record

Assuming that a patient has justifiable grounds for having a note in the record changed, how should it be done in order to protect both the interests of the hospital and of the patient?

In one sense we are talking about a retraction, and it might be useful to look at the law in this regard. Under common law, retractions generally do not serve as a defense in a libel suit, unless they are made almost contemporaneously with the defamatory statement and are so closely connected with it

that the retraction negates the defamatory utterance itself. A retraction may also serve to mitigate damages.²⁷ It is generally agreed that for a retraction to serve any meaningful purpose it must be frank and unequivocal. It cannot be merely a publication of the true facts, but must be in effect an apology and leave no doubt that the original statement was false. It must also be given equal publicity, time and space with the original publication.²⁸

Let us look at some of the alternative procedures we have for changing a note with retractions in mind: 1) erasing the note completely, 2) crossing it out, 3) writing an addendum. If one resorts to erasure as a means of obliterating inappropriate statements, a retraction would not be needed. The medical record, unlike a newspaper article, has not been published, and an erasure would certainly "negate the utterance itself." However, this would be a risky procedure, as there would be nothing to prevent the hospital from maliciously erasing notes which might lead to lawsuits. Most guidelines for medical record librarians warn against erasures as likely to arouse suspicion.²⁹ However, this is the only procedure which would seem to fully protect the patient's interest, as only total obliteration would protect him from future prejudices of providers. Nonetheless, the arguments against it are too compelling. Allowing erasures in the record would open up a Pandora's box for hospitals or physicians to erase notes at will. It may also be in the patient's interest to let the note stand but amend it, since it could then be used by both patient and the state in possible legal proceedings against the hospital or physician. Merely crossing the note out is fraught with the same difficulties. For instance, how does one know when the note was crossed out, by whom and for what reason?

The third possibility, adding an addendum, is the method recommended by Hayt and Hayt in *Legal Aspects of Medical Records*.³⁰ They recommend that any alterations requested by the patients be made by adding an addendum to the chart indicating the change and that it was requested by the patient. The reason for indicating that the alteration is being made at the patient's request is that the burden of explanation for the change would fall on the patient rather than the hospital. This would protect the hospital from charges of tampering with the record. But are the patients' interests fully served? By this system the note would be corrected, but it could still prejudice future readers of the chart in their feelings toward the patient, e.g., "oh, this one must be a trouble-maker."

Perhaps the answer lies in looking at the criteria used by some courts in deciding what constitutes a retraction. It has been held that a statement of fact contrary to the original statement does not constitute a retraction.³¹ If a note is merely written indicating the patient's side of the story, as suggested above, this would not constitute a retraction. A full apology must be present. In this case, it is unlikely that we would want the hospital to apologize *per se* for the statement. However, as with a retraction in a libel suit, it seems reasonable that the corrected note should unequivocally state that the impression was wrong and should clearly show what the correct circumstances are. There is certainly precedent for this in current medical practice. Notes are "corrected" as diagnoses are eliminated by new findings such as negative test results. The physician merely states the fact in the chart. In a sense, this is a correction, and no one objects to this. One could argue, however, that as long as the past note remains, the patient's interests are not truly being served.

The only other possible solution is to isolate the note, as is done with psychiatric records, that is, store it in some secure place where it is not accessible, except when needed to serve

the patient, hospital or state's legal interest. This is somewhat impractical, for example how would one isolate one line from a chart? One answer is to cross out the statement so that it cannot be read as part of the chart and copy it into a record file which could contain all such altered notes. A note could be written in the chart indicating that a comment has been removed and stored elsewhere. Again, this is cumbersome.

... (since) notes can be legally changed, a way must be devised to protect the interests of all concerned.

A Proposal

Once one has determined that notes can be legally changed, a way must be devised to protect the interests of all concerned. Notes should not be changed whimsically, as both the hospital and the patient have a stake in a record which contains accurate and complete information. The procedure should be strictly delineated so that neither party can arbitrarily and unilaterally change information. Thus, if a note is to be changed, the physician and patient should discuss the change. If there is definite agreement that it should be changed, the notation should be rewritten, stating the reason why, and signed by both the *physician and patient*. It should be written in such a way that the physician clearly shows future providers that the change is justified, and that the patient is not merely a "trouble maker."

If there is no agreement between physician and patient, the dispute should be submitted to a panel consisting of the chief of the service, a psychiatrist, and a patient advocate who will determine whether it should be changed. (In this way, the truly "crazy" patient will not be able to manipulate the system.) If the panel determines that the note should not be changed, the patient should be allowed to write his own correcting note in the chart, stating that he disagrees with the first note, but that the panel did not perceive the change as being justified.

This procedure should resolve most of the problems presented. The hospital could not change a note with the intent of misinforming the patient as the patient would be involved in the process. The patient who wishes notes to be removed would have an opportunity to do so, but after an adverse decision by the panel he would still be able to state his case in the chart leaving it up to future providers to decide who was right. The process would not be needlessly cumbersome and bureaucratic.

Admittedly, some problems remain. One could argue that all cases should be submitted to a panel, rather than only those where disagreement between patient and provider exists. In this way neither the physician nor the patient could persuade the other to change a note inappropriately. However, many patients might be intimidated by having to resort to a formal panel, and practically speaking the procedure should be made as simple as possible for the patient, as well as for the provider. It could also be argued that in order for the panel to be totally objective, it should consist of people not associated with the hospital. This, however, would also serve as an impediment, since the more formidable a procedure seems, the less it will be utilized. We do not want to set up an obstacle course, but rather a practical procedure which will be used.

The issues are complex, but such a system might well protect the several interests represented, while remaining reasonably free of complexity and ambiguity.

Editor's Note: After this article was prepared, the U.S. Privacy Protection Study Commission issued its report *Per-*

CHANGING NOTES (Continued)

sonal Privacy in an Information Society. Its recommendations on medical record correction and amendment are consistent with the author's and appear in the box at right.

References

- 1 See, e.g., MASS. GEN. LAWS ANN., c. 111, §70 (hospitals and clinics licensed by health department required to keep records of the treatment of the cases under their care).
- 2 Accreditation Manual for Hospitals (JOINT COMMISSION ON ACCREDITATION OF HOSPITALS) p. 93.
- 3 Hirsh, H.L., *Medical Records - Their Medico-Legal Significance*, JOURNAL OF FAMILY PRACTICE 2 213-16 (1975) [hereinafter cited as Hirsh].
- 4 MASS. GEN. LAWS ANN., c. 111, §70 (except for hospitals under control of department of mental health, licensee must permit inspection of record by patient to whom record relates or by his attorney upon delivery of written authorization for patient); see Boston Globe, March 1, 1974, *Medical Records Available But Hospitals Make You Fight To See Yours*, at 1.
- 5 Shenken B.N., Warner D.C., *Giving the Patient his Medical Record A Proposal to Improve the System*, NEW ENGLAND JOURNAL OF MEDICINE 289 688-91 (1973).
- 6 Hirsh, *supra* note 3 at 214.
- 7 Hirsh, *supra* note 3 at 214.
- 8 See note 1 *supra*.
- 9 See note 2 *supra*.
- 10 20 CODE OF FEDERAL REGULATIONS §405.1026, MASS. REGS. vol. XIII, part 9, c. II 2.
- 11 See MASS. GEN. LAWS ANN., c. 111, §54 (department of public health empowered to order an audit of the medical records required kept under licensing provisions).
- 12 Rotan v. Greenbaum, 273 F.2d 830, 831 (D.C. Cir. 1959).
- 13 Report of the Secretary's Commission on Medical Malpractice (DEPARTMENT OF HEALTH EDUCATION AND WELFARE, publication no. OS 73-88) at p. 77.
- 14 Hirsh, *supra* note 3 at 214.
- 15 Pyramid Life Ins. Co. v. Masonic Hospital Ass'n of Payne County, 191 F. Supp. 51, 54 (W.D. Okla. 1961) (keeper of record not entitled to possess and use record to exclusion of patient, his representative or those standing in his shoes).
- 16 ANNAS, G.J., *THE RIGHTS OF HOSPITAL PATIENTS* 115 (1975).
- 17 Cannell v. Medical and Surgical Clinic, 315 N.E. 2d 278, 280 (Ill. App. Ct. 1974).
- 18 See note 2 *supra*.
- 19 See, e.g., Collins v. Meeker, 424 P.2d 488, 498 (Kan. 1967).
- 20 W. PROSSER, *THE LAW OF TORTS* 739 (4th ed. 1971) [hereinafter cited as PROSSER].
- 21 PROSSER, *supra* note 20 at 746.
- 22 PROSSER, *supra* note 20, at 738.
- 23 Berry v. Moench, 8 Utah 2d 191, 331 P.2d 814, 820 (1958).
- 24 See Roth v. Greensboro News Co., 217 N.C. 13, 6 S.E. 2d 882, 887 (1940) (honest mistake in publication of libelous article will not protect publisher).
- 25 PROSSER, *supra* note 20, at 786.
- 26 Gactano v. Sharon Herald Co., 426 Pa. 179, 231 A.2d 753, 755 (1967) (no cause of action for libel arises until publication of defamatory matter occurs).
- 27 Stone v. Essex County Newspapers, Inc., 311 N.E. 2d 52, 59 (Mass. 1974) (defendant may introduce evidence of retraction in mitigation of damages).
- 28 Roth v. Greensboro News Co., 217 N.C. 13, 6 S.E. 2d 882, 888 (1940) (retraction must be a full and fair correction; apology which clearly admits falsity of original article) Brogan v. Passaic Daily News, 22 N.J. 139, 123 A.2d 473, 478 (1956) (retraction must be in as public a manner as that in which defamatory charges were made).
- 29 E. HAYT & J. HAYT, *LEGAL ASPECTS OF MEDICAL RECORDS* 35 (2d ed. 1977).
- 30 *Id.* at 36.
- 31 Roth v. Greensboro News Co., 217 N.C. 13, 6 S.E. 2d 882, 887-88 (1940).

Relative to the correction of a medical record by a patient, the Privacy Protection Study Commission recommended in July, 1977 that an individual should be able to review his or her record and to correct or amend any errors prior to its release to third parties. Specifically, recommendations seven and eight apply to changing notations within a medical record:

Recommendation (7):

That each medical-care provider have a procedure whereby an individual who is the subject of a medical record it maintains can request correction or amendment of the record. When the individual requests correction or amendment, the medical-care provider must, within a reasonable period of time, either:

- (a) make the correction or amendment requested; or
- (b) inform the individual of it, refusal to do so, the reason for the refusal, and of the procedure, if any, for further review of the refusal.

In addition, if the medical-care provider refuses to correct or amend a record in accordance with the individual's request, the provider must permit the individual to file a concise statement of the reasons for the disagreement, and in any subsequent disclosure of the disputed information include a notation that the information is disputed and furnish the statement of disagreement. In any such disclosure, the provider may also include a statement of the reasons for not making the requested correction or amendment.

Finally, when a medical-care provider corrects or amends a record pursuant to an individual's request, or accepts a notation of dispute and statement of disagreement, it should be required to furnish the correction, amendment, or statement of disagreement to any person specifically designated by the individual to whom the medical-care provider has previously disclosed the inaccurate, incomplete, or disputed information.

Recommendation (8):

That when an individual who is the subject of medical-record information maintained by an organization whose relationship to the individual is not that of a medical-care provider requests correction or amendment of such information, the organization should disclose to the individual, or to a medical-care professional designated by him, the identity of the medical-care provider who was the source of the information; and further,

That if the medical-care provider who was the source of the information agrees that it is inaccurate or incomplete, the organization maintaining it should promptly make the correction or amendment requested.

In addition, a procedure should be established whereby an individual who is the subject of medical-record information maintained by an organization whose relationship to him is not that of a medical-care provider, and who believes that the information is incorrect or incomplete, would be provided an opportunity to present supplemental information, of a limited nature, for inclusion in the organization's record, provided that the source of the supplemental information is also included in the record.

Hospital Forum

Patient Privacy and the Media

By James F. Holzer, J.D.*

"Whatsoever things I see or hear concerning the life of man, in any attendance on the sick or even apart therefrom which ought not be noised about, I will keep silent thereon, counting such things to be professional secrets."

Hippocratic Oath

There can be no doubt that a tremendous amount of information is collected within the lifetime of all health care consumers, and today, people who are admitted to hospitals are seeking greater assurances that their relationship with the hospital and the physician is one of *confidence and trust*.

With the vast amount of personal information collected by hospitals and federal or state agencies, the effort to protect privacy has been gaining great momentum. Although Hippocrates attempted to address the issue within the ethical sphere of medicine, the *legal right* was first conceptually argued by U.S. Supreme Court Justices Louis Brandeis and Samuel Warren in an 1890 *HARVARD LAW REVIEW* article.¹ The so called "right to privacy," while not found directly in the Constitution, has served as the basis for numerous privacy decisions by the high court since that time.

Most hospital patients assume information about their care and treatment will be held confidential. This assumption, however, is occasionally an illusory one since hospitals routinely divulge basic information in the form of announcements to the news media, condition reports over the telephone to friends and relatives, and medical information to third-party payors.

As a general rule, there are four areas in which invasion of privacy has been prohibited:²

1. Use of another's name or likeness for personal gain.
2. Placing a person in false light.
3. Public disclosure of private facts.

*Mr. Holzer, a member of the Massachusetts Bar, is Assistant Administrator of the Massachusetts Eye and Ear Infirmary in Boston, and an Assistant Professor in Rehabilitation Medicine, Tufts University School of Medicine.

4. Intrusion upon a person's right to be left alone.

It is within these last two areas that hospital public relations practitioners and administrators are becoming more cognizant of the delicate balance between "private rights" and "public interest."

Historically, the terms "public interest" or "public record" have been key issues when deciding a person's private life can no longer be shielded by the law. The media historically has exercised certain constitutional privileges in reporting facts about individuals who are under the public eye. Unless the media intrudes upon the privacy of an individual by making statements known to be false or in reckless disregard of the truth, the individual generally has no private right of action against the newspaper or publisher of this information.³ For years, people involved in incidents of *public record* such as traffic accidents, news stories, or police matters, were generally thought to be within the public interest.

In its publication, *A Guide for Cooperation with Communication Media*, published by the American Hospital Association in 1969, these principles were reflected in the overall philosophy and procedures outlined in the guidebook.

Consequently, hospital PR practitioners have been advised that there is probably no harm in releasing certain basic information about individuals who are thrust into the public limelight, whether voluntarily or involuntarily. In other words, the public's *right to know* has outweighed the individual's constitutional *right to be left alone*. Many court decisions have supported this concept making journalists and media sources comfortable in releasing information that is in the public interest so long as it can not be considered highly offensive.

The pendulum, however, appears to be swinging the other way. Within the past ten years, we have seen some subtle developments in the area of privacy which may potentially force hospitals to change their practice in releasing patient information to the media. These changes can be summarized by examining five major issues in the problem.

Breach of Confidentiality

For centuries, it has been an implied understanding that a physician will not disclose information to anyone not directly involved in the care and treatment of the patient. Naturally, the physician must give information of a medical nature and must document his own actions in the medical record. If the physician oversteps his bounds, there is the possibility of legal action. It is obvious then that the doctor is permitted to disclose otherwise confidential information about his patient to the *hospital* since the hospital and its staff are directly connected with the care and treatment of that patient. However, disclosure by the physician to any person or organization other than the hospital might be a breach of confidentiality unless there was some supervening interest of society or consent by the patient.⁴ It follows that if the physician can be sued for releasing this information to someone not connected with the care of his patient, then the hospital, which appropriately received this same information, might be liable for releasing portions of it to the public or the media.

How does a hospital arrive at a patient condition report? Obviously, the one word condition such as "good," "fair," or "danger list," is based on information that the physician and hospital have obtained in the examination, care, and treatment of the individual. Similarly, in order for the hospital to release to the media or public the *nature* of an individual's injury as recommended in the A. H. A. Guidelines, such as *head injury*, *puncture wound* etc., it is necessary for the physician or hospital staff to first make a professional observation and diagnosis. If the hospital wished to give the media a complete copy of the patient's diagnostic tests, confirming the diagnosis of "head injury" without the patient's consent, we would be correctly advised that this information would be confidential and could not be divulged. Yet, many hospitals have a common practice of releasing the most important part of those confidential tests and reports — namely the *final diagnosis itself* — in the case of so called "public record" cases.

The "Public Record" Dilemma

As earlier stated, two of the four recognized areas of privacy relate to (a) public disclosure of private facts and (b) intrusion upon a person's right to be left alone. Some courts have also required the plaintiff to prove that the defendant invaded his privacy with "reckless disregard for the fact that a reasonable man would find the invasion highly offensive" and that the divulged information was not in the "public interest." However, the United States Supreme Court has ruled that interests in privacy fade when the information involved *already appears within the public record*.⁸ Thus, otherwise private and confidential information already in a public record may, ipso facto, be in the public interest. Accordingly, *an invasion of privacy would seemingly have to be an unreasonable interference, offensive to a reasonable man, and where the disclosed information is not in the public interest or the public record.*

As a matter of routine, many hospitals throughout the country release the patient's name, condition report, and general nature of injury on so-called "public record" cases, such as individuals who are brought to the hospital by city ambulance, or were involved in a car accident. Hospital officials must now ask themselves, do they release only the precise information *already* appearing on the public record or do they release any basic information on individuals whose injuries somehow got into a public record, such as a police report, etc.? In the case of accident victims, the public record is more than likely the police accident report which is filled out at the scene of the incident. Police seldom follow-up with hospital officials to record information such as the precise nature of injury after medical examination or the condition of the patient. Therefore, if the injury and condition are not required to be recorded in the public record, one might question why the hospital is allowed to automatically release this information without the patient's consent.

Accreditation Standards and Regulations

Internal regulations within hospitals are now addressing the issue of patient privacy. As an example, in the preamble of the standards published by the Joint Commission on Accreditation of Hospitals, JCAH states that "every individual who enters a hospital or other health care facility for treatment retains certain rights to privacy." The individual's dignity is reflected in the respect accorded by others to his need to maintain the privacy of his body." The Joint Commission con-

tinues by saying that "another important aspect of the patient's right to privacy is related to the preservation of the confidentiality of his disclosures." Similarly, the American College of Hospital Administrators has placed a heavy emphasis on privacy and consent. In the College's Code of Ethics, it is stated:

Fully recognizing that the press, radio, and other communications media are excellent vehicles of public education and have a responsibility to disseminate information to the community, the hospital must appreciate its moral obligation to the patient and to the professional groups represented in its organization. Consequently, information about patients, except as required by law or where privileged communications is involved, *should not be given without consent.*⁹

The Patient Bill of Rights

Most hospitals have adopted some type of Patient Bill of Rights similar to the document suggested by the American Hospital Association. It is significant to note that *Principle V* of the Patient Bill of Rights states that "the patient has the right to every consideration of his privacy concerning his own medical program." And *Principle VI* says that "the patient has the right to expect that all communications and records pertaining to his care should be treated as confidential." The Patient Bill of Rights and the preamble to the Joint Commission Standards have no real force and, in a court of law, they are simply guidelines and recommendations. However, it is possible for documents such as these to have legal significance if a court was to admit evidence of self imposed standards of care which the hospital must reasonably follow. (Under the rules of evidence, these standards and rights could serve as *evidence of custom* in the hospital industry, for the purpose of showing that a hospital fell below the *standard of care* owed to the patient.)

The Era of the Privacy Movement

One only need look at such Federal laws as the Privacy Act of 1974 (intended to give citizens more control over information and records on file with federal agencies), and the Freedom of Information Act, implemented in 1976 (making it possible for citizens to know the kinds of information being kept on them), to realize that the "privacy movement" is making a significant impact upon society. A number of states are also passing laws which would eventually make it easier for patients to have a cause of action against physicians and

hospitals for invasion of privacy. Many of these state statutes follow a format similar to the A.H.A. recommended Patient Bill of Rights. It is not difficult to envision further regulations giving the individual's right to be left alone a greater edge over society's right to have knowledge of private information.

The Importance of Consent

The five aforementioned issues are thus taking on greater significance when a hospital evaluates its media procedures. Ironically, there would be very little controversy and need for revised media guidelines, if hospitals would adopt a simple and effective patient consent procedure. Consent can either be what the law terms "express" (in writing or oral), or "implied" (inferred by conduct or lack of objection). Some hospitals in the Greater Boston area have already adopted a standard admission consent form informing patients that the hospital would release name, date-admitted, room number and a simple "one-word" condition report. The patient is told that he or she has a right to object to the release of this information. Hospitals having such a procedure report that, as a general rule, people do not object to having this information released after having it explained to them how and why it is being used. Other facilities are considering simply calling the patient's attention upon admission to the fact that certain basic information will be released as a service to friends and relatives concerned about the patient. It could be argued that the patient, by not making any objection when this statement is offered, has essentially given *implied consent* to release this information.

In emergency-ward cases and other matters that are in the so-called "public domain," one medical center in Boston will not release any information on public-record cases to the media until a reasonable attempt is made to get verbal consent either from the patient or next of kin. Where the media request occurs in the early morning hours such as three or four a.m., media is told that the hospital will call back later that morning to follow-up their request. According to this hospital, only a handful of patients involved in so called "public record" cases objected to the release of information to journalists. In each case, media representatives responded in a positive and cooperative manner when told that the patient preferred this information to remain confidential. This reaction is not surprising when one considers that the news media was a major contributing

(continued on page 11)

Hospital Forum

(continued from page 9)

force behind the development of expansive privacy laws on a national and regional level.

In my involvement with this issue for the past three years, the greatest resistance to stronger privacy procedures in the hospital public relations office has come from those facilities which appear to have an insecure and troubled relationship with the local media. In some parts of the country, there appears to be great reluctance on the part of the hospitals to change procedures which allow release of information from the accident room for fear that journalists will take vengeance at annual-report time, or during the hospital building and fund raising program. A small number of hospitals in fact still continue the old practice of releasing automatically to the local newspaper names and addresses of all patients admitted to the facility. Consequently, there is a great need for improved dialogue between many hospitals and the news media so that both industries are open and willing to jointly accept change and vary from procedures developed decades ago.

The American Hospital Association, the American Society for Hospital Public Relations, and regional hospital associations such as the Hospital Council of Western Pennsylvania,¹⁰ are presently reviewing or revising media/privacy procedures so that the interests of the patient and society can be met equitably and consistently.

References

1. Brandeis and Warren, *The Rights to Privacy*, 4 HARV. L. REV. 193 (1890).
2. Prosser, *Handbook of the Law of Torts* 317 (4th Ed. 1970).
3. *Time, Inc. v. Hill*, 385 U.S. 374 (1966).
4. *Horne v. Patton*, 287 So. 2d. 824 (1973).
5. *Briscoe v. Readers Digest Ass'n*, 483 P.2d 34 (1975).
6. *Cox Broadcasting v. Cohn*, 420 U.S. 469 (1975).
7. See generally, *ACCREDITATION MANUAL FOR HOSPITALS* (JCAH, Chicago, 1978).
8. See generally, *AHA-ACHA, CODE OF ETHICS*.
9. Annas, G.J., *THE RIGHTS OF HOSPITAL PATIENTS* (American Civil Liberties Union, New York, N.Y.) (1975) at 25.
10. See *GUIDELINES FOR THE RELEASE OF INFORMATION TO THE COMMUNICATIONS MEDIA* (Pittsburgh, 1978).

Washington Report

(continued from page 10)

gers of pesticide misuse was substantiated in 1963 by President Kennedy's Science Advisory Committee.

In the same issue, there is an article describing the efforts EPA is making to study pesticide residues in mothers' milk. Chlorinated hydrocarbons such as DDT, dieldrin, chlordane, and heptachlor have been found in samples of mothers' milk in increasing quantities. Even trace amounts of these chemicals could be hazardous to infants because their livers are less able to filter out these substances. Rachel Carson was severely criticized for speaking out against the polluting of the environment because she laid the blame for the problem on pesticides, DDT in particular. However, these same chemicals also have their strong supporters. Use of pesticides has helped to greatly increase agriculture production and, in some cases, has even saved lives.

William Tucker writing in *Harper's*, August 1978 ("Of Mites and Men") has another explanation for the criticism of Carson and other environmentalists. In *Silent Spring*, "the future excesses of environmentalism appear in embryonic form on every page." These excesses can be reduced to three myths that the environmental movement has fostered. First, that there was a time when pesticides were not used, crops grew in abundance, and there was little health problem from pests. Second, Tucker points to the false distinction environmentalists make between "natural" and "unnatural" chemicals, and claiming further that the latter do not occur in nature. The third myth is that these same "unnatural" chemicals "are causing an equally mythical epidemic increase in cancer." Tucker likens the environmental protection movement to a secular religion strongly influenced by a Puritan strain, by which he means it is built more on what we don't know than on what is proven. This produces a panic fear of all pesticides that does not properly consider the benefits that are derived from their use.

The *Wall Street Journal*, in a recent editorial, blamed recent insect epidemics on "the radical fringe of the environmental movement (that is) giving the country back to the bugs." The *Journal* advocated the wholesale use of chemicals to kill insects. The obvious question which the *Journal* ignored is if these chemicals

are toxic enough to kill insects, what can they do to other living creatures? Pesticide regulation under FIFRA is based on the premise that a product cannot be registered unless it will not pose an unreasonable risk of harm to health or the environment. The applicant for registration must submit data to establish this. EPA has been plagued by companies submitting falsified test data to prove this lack of risk of harm. Congress knew this when it enacted the 1978 amendments. It could have strengthened FIFRA significantly. Instead it chose to weaken the law by turning more of the pesticide regulatory responsibility over to the states, ignoring or indifferent to the fact that some of the worst abuses of pesticides occurred in the days when the states possessed this regulatory function.

As to the claim that the environmental movement is based on ignorance, that is a curious argument for industry to make. It concedes that the same industry that makes the chemicals that enter the food chain doesn't know what harmful effects are associated with them. It is the ignorance of industry that should be the focus of attention. They are the people who introduce the risk. They are the ones who should be able to tell us how great the risk is.

When dealing with substances that can cause serious illness and death over a 20 to 30 year exposure, error on the side of caution is the only prudent approach. Industry can minimize this error by vigorously testing substances rather than piously claiming that the environmentalists lack proof of harm.

To Contributors

MEDICOLEGAL NEWS welcomes original manuscripts dealing with current or emerging issues or problems in the field of legal medicine and the ever-expanding interrelationships between law, medicine and health care. Acceptable subjects include health law and policy; legal, ethical, and social aspects of medical practice, medicolegal education or research; health insurance; and medical malpractice.

Manuscripts or letters-to-the-editors should be submitted double spaced, in typewritten form and with two copies. All inquiries should be addressed to: Managing Editor, MEDICOLEGAL NEWS, 454 Brookline Avenue, Boston, MA 02215.

C. LETTER FROM JOHN E. AFFELDT, M.D., PRESIDENT, JOINT COMMISSION ON ACCREDITATION OF HOSPITALS, SUBMITTING STATEMENT ON PRIVACY OF MEDICAL RECORDS LEGISLATION

**Joint
Commission**

875 North Michigan Avenue Chicago, Illinois 60611
on Accreditation of Hospitals (312) 642-6061

John E. Affeldt, M.D.
President

August 20, 1979

Honorable Richardson Preyer, Chairman
Government Information & Individual Rights
Subcommittee
Committee on Governmental Operations
United States House of Representatives
Rayburn House Office Building
Room B-349-B-C
Washington, D.C. 20515

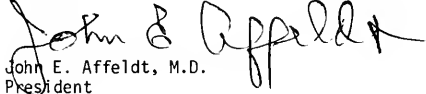
My Dear Mr. Preyer:

Please refer to your letter of May 2, 1979 seeking the comments of the Joint Commission on Accreditation of Hospitals (JCAH) on HR.2979 and HR.3444, two bills to protect the privacy of medical records.

We respectfully ask that our attached statement on this matter be included in the hearing record dealing with this legislation.

Thank you for this opportunity to comment on the important issues raised by these bills.

Sincerely,


John E. Affeldt, M.D.
President

PEM:JEA/bc
Attachment

Member Organizations

American College of Physicians
American Hospital Association

American College of Surgeons
American Medical Association



875 North Michigan Avenue Chicago, Illinois 60611
 on Accreditation of Hospitals (312) 642-6061

John E. Affeldt, M.D.
 President

STATEMENT
 OF THE
 JOINT COMMISSION ON ACCREDITATION OF HOSPITALS
 ON HR.2979 AND HR.3444
 FEDERAL PRIVACY OF MEDICAL RECORDS ACT
 AND THE
 PRIVACY OF MEDICAL INFORMATION ACT
 BEFORE THE GOVERNMENT INFORMATION AND INDIVIDUAL RIGHTS SUBCOMMITTEE

Mr. Chairman, I am John E. Affeldt, M.D., President of the Joint Commission on Accreditation of Hospitals (JCAH). I am pleased to have the opportunity to present the views of the Joint Commission to the Committee on Governmental Affairs on HR.2979 and HR.3444, the Federal Privacy of Medical Records Act and the Privacy of Medical Information Act.

JCAH/HISTORICAL BACKGROUND

Before addressing myself to this legislation, I would like to present background information about JCAH. In 1951 the American College of Physicians, the American Hospital Association, the American Medical Association, and the Canadian Medical Association (which withdrew in 1959 to participate in its own national hospital accreditation program) joined with the American College of Surgeons to form the Joint Commission on Accreditation of Hospitals. The JCAH was incorporated in Illinois as a not-for-profit corporation.

Member Organizations

American College of Physicians
 American Hospital Association

American College of Surgeons
 American Medical Association

As stated in Article I of its Bylaws, the purposes of JCAH are:

- (1) to establish standards for the operation of hospitals and other health-related facilities and services;
- (2) to conduct survey and accreditation programs that will encourage members of the health professions, hospitals, and other health-related facilities and services voluntarily to
 - (A) promote high quality of care in all aspects in order to give patients the optimum benefits that medical science has to offer,
 - (B) apply certain basic principles of physical plant safety and maintenance, and of organization and administration of function for efficient care of the patient,
 - (C) maintain the essential services in the facilities through coordinated effort of the organized staffs and the governing bodies of the facilities;
- (3) to recognize compliance with standards by issuance of certificates of accreditation;
- (4) to conduct programs of education and research and publish the results thereof, which will further the other purposes of the corporation, and to

accept grants, bequests, and devises in support of the purposes of the corporation; and

- (5) to assume such other responsibilities and to conduct such other activities as are compatible with the operation of such standard-setting, survey and accreditation programs.

This voluntary approach to quality assurance is unique to the United States and Canada. Other countries have approached quality assurance through government regulation, whereas, in this country health providers took the initiative to use the voluntary approach, which has resulted in an effective system of coordination between the public and private sectors.

Role of JCAH

In addition to its Hospital Accreditation Program, the JCAH also establishes standards and offers voluntary accreditation programs throughout the United States for adult psychiatric facilities, children's and adolescents' psychiatric facilities, drug abuse treatment and rehabilitation programs, alcoholism treatment and rehabilitation programs, community mental health services, long term care facilities, mentally retarded and other developmentally disabled persons, and ambulatory health care organizations. Collectively the accreditation programs of the Joint Commission survey over 4,500 facilities, services and programs in the course of a year, and approximately 7,300 facilities, services and programs currently hold JCAH accreditation. Represented in this statistic are over 70% of the hospitals in the United States.

It should be recognized that JCAH, rather than directly involving itself in the evaluation of patient care and services, fixes the responsibility for performance of these functions with the hospital and its organized medical staff. The accreditation process of JCAH is a significant mechanism through which providers of health care and related human services have been effectively motivated through voluntary professional efforts to provide higher levels of quality and service.

Hospital Accreditation Program Standards

The JCAH standards for hospital accreditation as contained in the Accreditation Manual for Hospitals, 1979 edition, have a long history of development. The first "Minimum Standard for Hospitals" was issued by the American College of Surgeons (ACS) in 1917. During the following 35 years ACS conducted a Hospital Standardization Program which caused a natural evolution in hospital standards. In 1952 when the JCAH survey program was implemented these minimum standards of the ACS program were utilized.

The adopted minimum standards were revised six times by the JCAH Board of Commissioners between 1953 and 1965. Then in August 1966, the Board of Commissioners voted "to review, re-evaluate, and rewrite the hospital accreditation standards and their supplemental interpretations to raise and strengthen the standards from a level of minimum essential to the level of optimal achievable and to assure their suitability to the modern state of the art."

Consequently, the standards underwent extensive revision, resulting in the 1970 edition, called, for the first time, the Accreditation Manual for Hospitals (AMH).

Since then, the Manual has undergone continuous review and revision to keep abreast of the state of the art.

COMMENT ON HR.2979 AND HR.3444

JCAH standards have always emphasized the confidentiality of patient records. Our Accreditation Manual for Hospitals contains seventeen references covering fourteen hospital departments stressing the importance of this matter and generally requiring that the facility and the appropriate Departments be able to demonstrate a mechanism for insuring that medical records are maintained in a confidential and secure manner. Mr. Chairman, we submit that the JCAH standards and survey process demonstrate a positive and constructive voluntary endeavor to achieve the objectives sought by subject proposed legislation.

Our specific comments on some of the important issues raised by this legislation follow.

DEFINITIONS

The definition of accounting in Section 101(1) HR.2979 may be interpreted as requiring that disclosure recording be an integral of the record of the patient's clinical progress. We interpret one objective of this legislation as being to insure that a patient may discover the disclosure history of the record pertaining to his care. We submit that the essential element of this objective is that disclosure accounting be accomplished in a fashion designed to achieve this objective. The prescription of this legislation is but one approach. In this connection we note that HR.3444 does not contain a definition for "accounting" and its reference to this matter at Section 105(e) requires that a copy of the

disclosure authorization be made a part of the medical information maintained on an individual.

Recommendation. That HR.2979 be revised with respect to the matter of medical information disclosure accounting to be consistent with the relevant provisions in HR.3444 in order to minimize redundant "accounting" and to allow health facilities the latitude of selecting the most efficient institution specific means of achieving the legislative intent.

RIGHTS OF MINORS

The significantly different approaches to the definition of "minor" in Sections 103.HR.2979 and Section 310(10)(A) HR.3444 highlight the problems inherent in legislating community mores. While the HR.2979 approach, acceding to State law, is preferable, we are nonetheless convinced that a federal initiative in this area will create patient care and legal problems for health service providers. State laws which may be affected by this proposed legislation not only include those dealing with medical record privacy but also those treating with the age of majority, emancipated minors, and the protection of the confidentiality of the medical relationship with minors pertaining to venereal disease, pregnancy, drug abuse, alcoholism, rape and child abuse. This legislation has the potential for creating situations necessitating parental, guardian or third party access to medical records of minors treated for these latter conditions thereby discouraging minors from seeking the treatment they so urgently need. Further conflicts will arise because in some States a minor could consent to treatment under State law but be denied direct access to his medical record under this proposed Federal legislation.

Recommendations: That HR.2979 and HR.3444 defer to the standards established under the laws of each State for the definitions of majority and standards for access to the records of minors.

PATIENT ACCESS TO THE RECORDS OF HIS MEDICAL CARE

The JCAH Accreditation Manual for Hospitals (AMH) specifies "The patient has the right to obtain from the practitioner responsible for coordinating his care, complete and current information concerning his diagnosis (to the degree known), treatment, and any known prognosis. This information shall be communicated in terms the patient can reasonably be expected to understand. When it is not medically advisable to give such information to the patient, the information should be made available to a legally authorized individual." Elsewhere the AMH states "...Patients are entitled to information about the hospital's mechanism for the initiation, review and resolution of patient complaints."

Mr. Chairman, while JCAH standards do not require hospitals to either furnish a patient a copy of the records of his medical care or a mechanism for seeking an amendment to such record, the changes proposed in Section 111 HR.2979 and in Section 101 HR.3444 would be in accord with the spirit of our standards. We are persuaded that the practitioner responsible for the patient's care has a responsibility to communicate medical record information to his patient. In the best of all worlds said practitioner should review any record released to his patient with that individual. Under any circumstances it is clear that said practitioner must review such records in advance of their release to insure the appropriateness of the release of the entire record to the patient. This necessity is appropriately recognized in Section 111(b) HR.2979 and in Section 101(b) HR.3444.

The central issue before us is whether federal legislation is needed in this area. In this connection we would point out that: The law (statutory or judicial) of most states would recognize, if tested, a reasonable right of access to medical record information by the patient or his nominees; most hospitals and hospital medical staffs currently have policies governing access to patient care records in accord with the principles expressed in these legislative proposals; and for years hospitals have entertained requests from patients for correction or amendment of specific medical record information. Considering these facts the need for the instant legislative provision is not clear.

Section 111(a)(2) HR.2979 would enable a facility to require a written application for the inspection and copying of a medical record. Section 101(a) HR.3444 could be read as dictating that a facility comply with a verbal request.

Recommendation. That the language of Section 111(a)(2) HR.2979 be included in any final legislation in this area because we believe a provider should have the latitude to adopt a uniform policy and procedure appropriate to its publics.

Section 111(c) HR.2979 requires HEW to promulgate criteria by which medical facilities shall determine whether an individual should be denied personal access to the record of his care. This provision would seem to confer upon the Department a competence we would suggest is clearly more appropriate to the professional judgment of the patient's physician.

Recommendation. We recommend the legislation embody the approach contained in Section 101(b) HR.3444 delegating this determination to the facility because it

is more appropriate, and less costly. Further, appropriate access is still assured through a designated person in both bills.

NOTICE OF RECORD KEEPING PRACTICES

Section 113, HR.2979 and Section 103, HR.3444 deal with the subject of notifying patients of a medical facility's record keeping practices including record disclosures which shall be made absent specific authorization. HR.3444 seems to deal more thoroughly with this matter and includes a requirement that HEW develop an acceptable model notice. One troublesome and potentially costly feature of HR.3444, however, is the notification/renotification requirement. The only practical way for a facility to deal with this requirement is to notify every patient at every encounter.

Recommendation. We recommend adoption of the HR.3444 approach in this issue with further modification to permit the posting of multi-language notices in appropriate locations. We make this recommendation because it seems to be the least costly and most practical.

GENERAL DISCLOSURE LIMITS

Section 114, HR.2979 and Section 104, HR.3444 deal with general disclosure limits. Section 104 would seem to provide unlimited record access to properly identified Federal or State authorities.

Recommendation. That the provisions of Section 114, HR.2979 be adopted with respect to general disclosure limits because of the protection it affords patients with the limitation to disclosure of needed information only.

DISCLOSURES WITHOUT PATIENT CONSENT

The JCAH Accreditation Manual for Hospitals (1979 edition) contains the following statement: "The patient has the right, within the law, to....information privacy as manifested by the right to: ...have his medical record read only by individuals directly involved in his treatment or the monitoring of its quality, and by other individuals only on his written authorization or that of his legally authorized representative." This principle is further expanded in the Manual by "written consent of the patient or his legally qualified representative is required for release of medical information to persons not otherwise authorized to receive this information. This shall not be construed to require written consent for use of the medical record for automated data processing of designated information; for use in patient care evaluation studies, such as retrospective audit and medical staff monitoring functions; for departmental review of work performance; for official surveys for hospital compliance with accreditation, regulatory and licensing standards; or for educational purposes and research programs."

Employee Use

Both bills provide for disclosure of medical information, absent patient consent, to individuals involved in the patient's care and provider employees on a need to know basis. Neither bill makes it clear that medical school faculty, medical students and health professional students may have access to medical records pursuant to their academic and clinical study programs.

Recommendations. We recommend adoption of language in both bills designed to assure that medical education activities will not be disrupted by the operations of a privacy protection program.

Audits and Evaluations

While Section 125(a)(1) HR.2979 and Section 105(b)(7) HR.3444 would seem to allow access to patient records by JCAH surveyors absent patient consent, this fact is not sufficiently clear.

Recommendations. We recommend that the terms "audit" or "evaluation" in Section 125(a)(1) HR.2979 and Section 105(b)(7) HR.3444 be expanded to specify that these terms embrace a survey by the JCAH.

Compelling Circumstances

HR.2979 does not address the problem providers frequently face in establishing patient eligibility for various programs. Many elderly patients are neither able to communicate a needed authorization nor do they have a responsible person to act in their place.

Recommendation. That HR.2979 be expanded to cover the aforementioned problem. The provisions of Section 105(b)(22) of HR.3444 could be usefully incorporated into HR.2979.

GOVERNMENT ACCESS PROVISIONS

While we are not particularly troubled by the government access provisions of HR.2979 and HR.3444 we believe it significant to note that rather than further limiting such access, as the titles of this legislation might suggest, government officials would obtain an additional avenue of access to such records via the enforcement requirements embodied in Section 151, HR.2979 and Sections 105b(6) and 106(a) HR.3444.

OVERVIEW

Mr. Chairman, as we have stated above, the proposed legislation is consistent with the standards of the Joint Commission. This legislation seeks to achieve on a statutory basis the assurances of the preservation of the confidentiality of medical information toward which medical facilities seeking our accreditation strive on a voluntary basis. Aside from the endeavors of hospitals seeking JCAH accreditation there are recent hospital industry-wide guidelines relative to institutional policies for disclosure of medical record information which are entirely consistent with these legislative proposals. Finally, a number of States have codified medical record access and privacy rights.

Mr. Chairman, we believe that given the voluntary impetus in this area and recent State legislative initiatives, your committee may wish to reassess the need for this legislation. We would also urge your committee to thoroughly evaluate the cost consequences of this legislation as an integral to such a reassessment. We could be persuaded that the costs of the bureaucracy required to administer the legislation (including the attendant regulatory promulgation and policing functions) and the institutional costs of administering the mandated program will not be insignificant.

Mr. Chairman, we appreciate this opportunity to express our views on HR.2979 and HR.3444.

D. LETTER FROM MYLIO S. KRAJA, DIRECTOR, NATIONAL LEGISLATIVE COMMISSION, THE AMERICAN LEGION, SUBMITTING STATEMENT ON PRIVACY OF MEDICAL RECORDS LEGISLATION



★ WASHINGTON OFFICE ★ 1608 "K" STREET, N.W. ★ WASHINGTON, D.C. 20006 ★



For God and Country

September 27, 1979

Honorable Richardson Preyer, Chairman
Subcommittee on Government Operations
& Individual Rights
House Committee on Government Operations
B-349-C Rayburn House Office Building
Washington, DC 20515

Dear Chairman Preyer:

The American Legion appreciates the opportunity to present testimony on H.R. 2979 and H.R. 3444, bills to protect the privacy of medical records and to amend the Privacy Act of 1974. In lieu of a personal appearance we request that the attached statement be made a part of the official hearing record.

Your cooperation in response to our request is appreciated.

Sincerely,

A handwritten signature in dark ink, appearing to read "Mylio S. Kraja". The signature is fluid and cursive, written over the typed name.

Mylio S. Kraja, Director
National Legislative Commission

Enclosure

STATEMENT OF ROBERT E. LYNCH, DIRECTOR
NATIONAL VETERANS AFFAIRS AND REHABILITATION COMMISSION
THE AMERICAN LEGION
TO THE SUBCOMMITTEE ON GOVERNMENT INFORMATION AND
INDIVIDUAL RIGHTS, COMMITTEE ON GOVERNMENT OPERATIONS,
HOUSE OF REPRESENTATIVES
SEPTEMBER 27, 1979

Mr. Chairman and Members of the Subcommittee:

We appreciate the opportunity given The American Legion to present its views on H.R. 2979 and H.R. 3444, bills to protect the privacy of medical records, to amend the Privacy Act of 1974, and for other purposes.

Before proceeding further, Mr. Chairman, The American Legion wants it made clear that it is in full accord with the general findings and purposes expressed in these measures that -

- 1) The right to privacy is a personal and fundamental right protected by the Constitution of the United States;
- 2) The collection, maintenance and use, and dissemination of medical information can threaten an individual's right to privacy;
- 3) The Federal Government is playing an increasingly important role in the provision, payment, and regulation of medical services;
- 4) Individuals should be able to exercise control over confidential medical information, particularly since the availability of such information to third parties may affect the individual's ability to obtain employment, insurance, medical care, and other benefits;

5) An individual's right to privacy must be balanced against the legitimate needs of public and private organizations for individually identifiable medical information in performing their law enforcement, public health, research, and other important functions; and

6) There is a need for Federal statutory protection of the privacy of medical information maintained by health care providers.

In view of the fact that The American Legion has not been asked to participate in open hearings on these measures, there appears to us that there is a question of whether the Legion, a war veterans' organization, has a legitimate or philosophical interest in their purpose. We believe that our interest in these measures is fundamental to the founding of The American Legion under a Congressionally approved charter, as amended. Among the several programs of The American Legion is the National Veterans Affairs and Rehabilitation program. This designates that phase of the organization's interest and activity concerned with war veterans, with particular reference to the care of the disabled and the welfare of their surviving dependents.

When first applied by The American Legion, the term "rehabilitation" related to the organization's efforts to secure for every veteran disabled in World War I the fullest measure of mental and physical rehabilitation that medical science could provide. The meaning of the term, as well as the name of the program, has since been broadened so that it now includes reference to vocational rehabilitation and education, social and economic

readjustment, and the welfare of veterans and dependents in general.

As used by the Legion today, the Veterans Affairs and Rehabilitation program refers to all the benefits and services which the organization has worked so hard to secure and maintain for those of service in WW I, WW II, the Korean Conflict, and the Vietnam Era.

More specifically, the term refers to the underlying intent and purposes of these benefits and services; that is, what they mean in terms of readjusting a war veteran to civilian life, restoring his health and his usefulness to society, maintaining his dignity and self-respect, and securing the economic welfare of his widow and children.

This program involves both assistance to the Nation as a whole, through its democratic processes, to shape a comprehensive and constructive program of veterans laws; and, assistance to eligible individuals - war veterans and their dependents and survivors - in securing the available benefits and services through a nationwide organization of American Legion service officers.

While the policies and practices of the Veterans Affairs and Rehabilitation program are determined by the membership as a whole, through its policymaking bodies, the program functions through a well organized nationwide network of specialized divisions of The American Legion on the Post, Departmental, and National levels.

At the Post level, there is provision for a Veterans Affairs and Rehabilitation Committee and a Post Service Officer. Similarly, every

Department has its Rehabilitation Committee and Department Service Officer; the majority have full-time paid staffs headed by a Rehabilitation Director. On the National level of The American Legion Veterans Affairs and Rehabilitation Commission, conduct of the program is primarily the function of the full-time staff of the Commission.

The community Post Service Officer is the backbone of the program for the reason that he is in the position of providing person to person help to veterans or their dependents in originating claims or in their subsequent development.

In these claims, the Post Service Officer must work hand in hand with his Department Service Officer who is a specialist in the prosecution of claims under the administration of the Veterans Administration, and whose office is in the VA Regional Office having jurisdiction of the claimant's residence. In turn, the Department Service Officer works in cooperation with the staff of the National Veterans Affairs and Rehabilitation Commission when claims in which he is involved are forwarded for consideration in the VA St. Paul and Philadelphia Insurance Centers, VA Central Office, the VA Board of Veterans Appeals, or to the Armed Forces Discharge Review Boards or Boards for the Correction of Military Records.

Within the structure of Veterans Affairs and Rehabilitation program services is a provision for accreditation of representatives of The American Legion for the preparation, presentation and prosecution of claims. Normally,

this accreditation is restricted to those representatives who have a need for access to the claimant's records.

Authority for their recognition originated in section 19 of the World War Veterans Act of 1924, PL 64-242, now codified in 38 USC 3402. It reads -

"The Administrator may recognize representatives of x x x x x x x The American Legion x x x x x x x x and such other organizations as he may approve, in the preparation, presentation, and prosecution of claims under laws administered by the Veterans Administration.

"The Administrator may, in his discretion, furnish, if available, space and office facilities for the use of paid full-time representatives of national organizations so recognized.

"No individual shall be recognized under this section -

"1) Unless he has certified to the Administrator that no fee or compensation of any nature will be charged any individual for services rendered in connection with any claim; and

"2) Unless, with respect to each claim, such individual has filed with the Administrator a power of attorney, executed in such manner and such form as the Administrator may prescribe."

Under this criteria of accreditation, any claimant may file a Power of Attorney with The American Legion at the Post, Department, or National level and be assured that a representative will assist him fully in the preparation, presentation, and prosecution of his claim. Within this

Power of Attorney-claimant relationship, representatives review each action as the claim is in process to assure that it is fully developed and equitably and properly disposed of. If the claimant or the organization representative express disagreement with the decision at the regional office level and appeal to the Administrator, a representative of The American Legion staff appears in his behalf before the Board of Veterans Appeals.

Under authority of sections 1552 and 1553 of title 10, United States Code, representatives accredited by the Administrator under 38 USC 3402, are recognized to act as counsel when so designated on DD Forms 149 and 293, petitioning the Secretaries of the Armed Forces for an upgrade of character discharges or separation or for correction of an Army, Naval, or Air Force record. Normally, these petitions with associated development and designation of counsel, originate at the Post or Department level.

A review of cases adjudicated by the VA regional offices and by the Board of Veterans Appeals will reveal that actual representation is performed by non-lawyers, service organization representatives experienced in matters pertaining to veterans affairs. Generally, representation is expert, nontechnical and with an awareness of precise issues. Accredited service organization representatives devote their full time to the task of serving claimants, and their performances, thus far observed, have been of high calibre. It is apparent that individual cases are thoroughly studied and the facts, no matter how detailed and medical in form, are well understood.

Aided by their intimate knowledge of VA administration procedures, regulation, and law, the accredited representatives have developed an able specialized bar.

In the filing of a Power of Attorney, the claimant authorizes access of his designated representative to all of the records which are available to the Veterans Administration in the adjudication of his entitlement or eligibility for benefits. The VA Power of Attorney Form 2-22 also carries the provision, when so authorized by the claimant, for release of such information to the Post Service Officer as is necessary to the development of the claim.

This is an important authorization by the claimant on VA Form 2-22 since Post Service Officers normally are not accredited. As an illustration, The American Legion has approximately 16,000 Posts. Of these, about 60 percent have an appointed Post Service Officer. And, as of July 1, 1979, only 974 accreditations by the Administrator of Veterans Affairs have been issued to representatives of The American Legion.

Since authorization under the World War Veterans Act of 1924, accredited representatives of The American Legion have participated in the preparation, development and presentation of claims before the VA and other agencies in accordance with criteria relating to confidentiality of records, and since the effective date of 5 USC 552a, privacy of records. To our knowledge, we have not been accused of disclosures from any claimant's medical or other records that violated the principles of confidentiality or

privacy as required by law or by other ethical or moral precepts.

As you know, Mr. Chairman, we are an organization of nearly 2.7 million war service veterans with an Auxiliary of nearly 1 million members. We believe that this membership of just under 4 million presents a good statistical consensus of a war veteran population of approximately 24 million. As of this date, we have not seen one expression of violation of confidentiality or of an individual veteran's privacy in the preparation, development or presentation of his claim for VA eligibility for benefits, or petitions under the discharge upgrade or correction of records programs.

Following this somewhat lengthy prologue, we now want to voice our concerns with some of the effects of the two measures on our ability to continue to provide the services of our representatives - accredited and non-accredited - to claimants for VA benefits or to those who petition the Armed Forces boards outlined above.

One of our concerns is related to the possible limitations on the VA Power of Attorney (2-22) filed by a claimant, appointing, say, The American Legion. Nothing in the language of either of these acts assures continuation of access of the accredited representatives of the Legion to medical records, nor do they assure authority to authorization, if so executed by the claimant, to release developmental data or information to the Post Service Officer designated.

We are concerned too, with the "specificity" provisions that would control the release of information from medical records of, say the Armed

Forces, to the VA for either treatment or entitlement to benefits adjudication. In general, most ex-service personnel, or those veterans under VA medical care, are vague on specific diagnoses or, in the case of incidents long past, as to specific dates or locations. We believe that the current regulations or procedure are in the best interest of the claimant. Under a general statement of disability treatment during a given period of active duty on VA Form 21-526, the VA receives the entire health or treatment episode record. Not infrequently, the veteran's recall is proven to be inaccurate. In addition, the alert claims or appeals representative, on receiving the total service medical record, may enlarge on the veteran's initial claim for benefits.

As we read the language of H.R. 2979, there is some question as to whether there is an adequate consent on execution of VA Form 21-526 for the Veterans Administration to procure medical records from its own medical records or from those of other Federally funded health care providers.

Under current VA procedures VA medical facilities may exchange information and transfer records between its several medical facilities, as well as with benefits personnel in the VA regional offices. As we read the provisions of H.R. 2979, a general reference by a claimant on VA Form 21-526 or on a supplemental claim, would not be sufficient to permit transfer of or exchange of medical information. Also, routine information on admission, extended stay, post surgical, etc., as currently provided to increase, extend, or reduce monetary VA benefits would be prohibited without specific beneficiary consent. We believe this would be disadvantageous both to the

beneficiary as well as to the Federal Government.

In summary, Mr. Chairman, insofar as the interests of our constituents are concerned, we object strongly to the effort to amend the Privacy Act of 1974 in such a way as to abandon the concepts of systems of records and "routine uses" so that unconsented-to disclosure of VA patient medical records could only be accomplished under the numerous narrow exemptions authorized under these measures.

And finally, Mr. Chairman, The American Legion, over the five decades following establishment of the Veterans Administration, has strongly supported the concept that the VA be an independent agency for the administration of all programs related to the administration of veterans benefits authorized by the Congress of the United States.

As we analyze H.R. 2979, the Secretary of HEW would have authority to write regulations implementing the bill after enactment. Several of such regulations would directly affect VA operations. At most, VA would be limited to comment on those regulations as affected VA operations directly.

With respect to this authority of the Secretary of HEW, it is suggested that it be limited or narrowed to the authority that it be only of an advice or guideline nature or that it be acceptable to the Administrator of Veterans Affairs.

Mr. Chairman, may I repeat, The American Legion has no opposition to the general purpose of these measures. It does though strongly object to those provisions which would materially affect the ability of our service

representatives to provide effective gratuitous assistance to VA claimants or to the procedures between the VA and the Armed Forces to expeditiously develop and adjudicate claims for benefits dependent on honorable service in the Armed Forces during a period of war.

We thank you for the opportunity given to express our views.

E. LETTER FROM DALE TOOLEY, DISTRICT ATTORNEY, SECOND JUDICIAL DISTRICT, STATE OF COLORADO, SUBMITTING TESTIMONY ON PRIVACY OF MEDICAL RECORDS LEGISLATION

DALE TOOLEY
DISTRICT ATTORNEY

SECOND JUDICIAL DISTRICT
WEST SIDE COURT BUILDING
924 WEST COLFAX AVENUE
DENVER, COLORADO 80204



State of Colorado

OFFICE OF THE DISTRICT ATTORNEY
DENVER

Administrative Offices.	(303) 575-5176
Appellate Division	" 575-5933
Community Relations and	"
Crime Prevention Division	" 575-3220
Complex Prosecution Unit	" 575-3291
Consumer Fraud Division	" 777-3072
County Court Witnesses	" 575-3074
Criminal Complaint Dept.	" 575-5624
(Police Dept. Office)	" 575-3541
Child Support Division	" 575-5821
County Court Deputies	" 575-5155
District Court Deputies	" 575-5135
District Court Witnesses	" 575-2349
Investigations Division	" 575-5956
Juvenile Court Deputies	" 575-5157
Juvenile Division	" 575-3220
Subpoenas	" 575-5851
City & County Bldg. Office	" 575-5951
Information	" 575-5824
Weekends & after 5 p.m. call	" 575-5555

September 27, 1979

Mr. Robert Gellman
Government Information and Individual
Rights Subcommittee of the Committee
on Government Operations
Rayburn House Office Building, Room B-349-B-C
Washington, D. C. 20515

Dear Bob:

Enclosed you will find a copy of the prepared testimony which I presented to the Senate Committee on the medical privacy issue. I do not have a copy of the transcript of the questions following the formal statement, but I have reviewed a draft of those proceedings and think that some of that may be as helpful as the enclosed.

I continue to feel that legislation in this area is much more detailed and complicated than is necessary. People in the field will perform better, I believe, if the legislation is shorter and more simply set forth, than if every possible problem is attempted to be solved in the legislation. I also believe that Congress should be very cautious about authorizing the promulgation of rules and regulations by HEW in this area, because so often regulations seem to complicate and sometimes contradict Congressional intent.

Yours truly,

Dale Tooley

DT:JH

DALE TOOLEY
DISTRICT ATTORNEY

SEVENTH JUDICIAL DISTRICT
WESTERN COURT BUILDING
934 WEST CLARK AVENUE
DENVER, COLORADO 80204



State of Colorado

OFFICE OF THE DISTRICT ATTORNEY
DENVER

Administration Office	(303) 525-5170
Appellate Division	525-5911
Community Initiative Unit	
Citizen Reciprocity Division	525-5270
Complex Prosecution Unit	525-5261
Consumer Fraud Division	525-5072
County Court Witnesses	525-5074
Criminal Complaint Dept.	525-5824
(Police Dept. Office)	525-3543
Child Support Division	525-5821
County Court Deputies	525-5155
District Court Deputies	525-5135
District Court Witnesses	525-2349
Investigative Division	525-5256
Juvenile Court Deputies	525-5157
Juvenile Division	525-3229
Subpoenas	525-5851
City & County Bldg. Office	525-5093
Information	525-5824
Weekends & after 5 p.m. call	525-5555

TESTIMONY OF DENVER DISTRICT ATTORNEY DALE TOOLEY

BEFORE THE COMMITTEE ON GOVERNMENTAL AFFAIRS OF

THE UNITED STATES SENATE

CONCERNING MEDICAL RECORD PRIVACY BILLS S.503 AND S.865

Room 3302, Dirksen Senate Office Building
10:00 a.m. June 27, 1979

I. INTRODUCTION

Mr. Chairman and Members of the Committee:

Beginning in 1975, my office and a Denver grand jury commenced a large-scale investigation of the insidious business of theft of persons' private medical records. The investigation revealed that for more than a quarter of a century, at least one firm, Factual Services Bureau, Inc., engaged in a nationwide, multi-million dollar a year business of obtaining citizens' private medical records without their authorization, by false pretenses, and selling that confidential information -- mostly to insurance companies and their counsel. This testimony and these recommendations are made from

the perspective of this investigation and the ensuing criminal prosecutions, convictions, appeals and the signing into law in Colorado last week of a new medical records law.

While I strongly support the thrust and public policies contained in both S.503 and S.865, it should be made clear that the privacy issue relating to private medical records is far different in nature from complex law enforcement and investigation issues raised in other pending legislation dealing with third party search warrants and financial records.

II. NATURE AND SCOPE OF THE PROBLEM

According to sworn testimony given in the course of our investigation, Factual Services Bureau was a firm which grossed up to \$3 million annually and which operated out of regional offices in 15 cities throughout the nation. Its "long suit" was securing medical records without the patients' authorization. Its customers were more than one hundred of the most prominent insurance companies in the nation, and often counsel representing those companies.

By obtaining medical information on claimants and potential claimants as early as possible, early claims reserves were able to be established. Even more important, the information was used by insurance companies to negotiate lower settlements of claims. Although

the insurers would normally have been able to secure most medical records information either by signed authorizations or by appropriate procedures in court, those steps took longer and were often more difficult than securing the records surreptitiously and without the patients' authorization. David Linowes, Chairman of the U.S. Privacy Protection Study Commission, described this widespread practice as "the insurance industry's Watergate."

The general mode of operation of investigators for Factual Services Bureau was to pose as doctors and to secure medical information by telephone from private, public and even military hospitals, from clinics, from doctors' offices and even from psychiatrists' offices. The firm had a training book on how to be an effective imposter in securing this information. To a somewhat lesser extent, paid "sources" (such as nurses or interns) were used to smuggle out medical files for copying or inspection, and sometimes false pretenses solicitations by the mails were used. These false pretenses methods were successful "99% of the time" by investigators for this firm.

To build its business, the firm sent out hundreds of form letters to insurance companies soliciting investigations and stating:

"In essence, our investigation reports cover all medical aspects of a claim, whether you have authorization or not."

Despite this broadside solicitation made in no uncertain terms, so

far as we were able to determine, no lawyer nor insurance company ever reported such solicitations to any law enforcement or regulatory authority. I find it difficult to believe that there are not or have not been similar enterprises engaged in this profitable, surreptitious business.

In the course of our investigation, my office executed a court-authorized search warrant at the now-defunct Denver office of Factual Services Bureau and seized almost two thousand reports to insurance companies -- in most of which patients' medical records, secured without their knowledge or authorization, were outlined in great detail.

As simply a couple of examples, attached is Exhibit "A", a Factual Services Bureau report to an insurance company detailing the medical information contained in hospital and a psychiatrist's records. Records from a California military hospital are described in this report, which even discloses the exact billing of \$3,991.36 for the patient's psychiatric services. The boldness with which these investigators secured the confidential information for their insurance company client can be seen from a paragraph on page 4 of Exhibit "A":

"We might add that under the California statutes, psychiatrists will not give out information on

a patient's treatment even with an authorization. If they do so, they can be subjected to a five hundred dollar fine."

The report then immediately launches into the very information contained in the psychiatrist's records.

Exhibit "B" involves the civil claim by a police officer who was blinded in a dynamite blast. This is one of the relatively few cases in our investigation where the patient had provided authorization to Factual Services Bureau. However, as can be seen from the discussion in the first few pages of the exhibit, the lawful methods were discarded and subterfuge was found to be more "efficient". On page 2 the investigator reports to its client:

"Somewhat perturbed at this lack of cooperation on both the part of the doctor and this hospital, we decided to quit wasting time to obtain records legitimately and once again directed our sources to pull the charts on the sly and photograph all the relevant parts."

On the same page the investigator boasts:

"In the matter of obtaining records, we are customarily requested by clients to determine medical information without authorization and have managed to develop very good channels over the years for this type of procurement."

In another typical report made to an insurance company client and to the law firm defending a claim, the investigators stated:

"We should caution the readers that this document is intended for your use only and should not be divulged in detail to other parties. The chart in question is extremely personal and of a volatile nature and should be treated as privileged information. Enough said."

In other instances, such reports to insurance companies acknowledged that the medical information was obtained "sub rosa" and that it should be treated as "strictly confidential".

III. SUBSEQUENT DEVELOPMENTS IN COLORADO

Investigators and agents of Factual Services Bureau were convicted of criminal conduct in Colorado, even though our statutes, typical of those of many states, were difficult to apply in this area of confidential information. However, our prosecutions of insurance companies were dismissed. The Colorado Supreme Court this year upheld the dismissals on the grounds that confidential medical information is not a "thing of value" under Colorado Criminal Code, and thus could not be the subject of criminal theft, even though the court found the insurance companies' conduct to be "reprehensible and outrageous". People v. Home Insurance Company, et al., No. 27984 (March 19, 1979).

In response to this decision, which was announced while the Colorado legislature was in session, we secured passage of H.B.1110, a medical records law, which may be the first of its kind

in the nation. It was overwhelmingly approved by the Colorado legislature, was signed into law by the Governor June 22, 1979, and takes effect July 1, 1979. A copy of the relevant portions of H.B.1110 are attached as Exhibit "C". The new law makes it clear that confidential information and medical records information, when obtained without proper authorization, constitutes felony theft. This act further places a duty on every corporation or person to promptly report a suspected crime to law enforcement authorities. In short, this statute reverses the Colorado Supreme Court decision in People v. Home Insurance Company, supra.

Factual Services Bureau has now dissolved and is no longer in existence. While we are satisfied that no remnants of that firm are operating in Colorado, without national legislation there can be little assurance that such activities will not go on elsewhere.

IV. S.503 and S.865 SHOULD MAKE IT A FELONY
TO TRAFFIC IN MEDICAL RECORDS

Section 216 of S.503 and §301 of S.865 both make it a misdemeanor to obtain medical records under false pretenses. However, misdemeanor penalties are not sufficient to deter adequately the kind of profitable, nefarious business in which Factual Services Bureau was involved.

Accordingly, I would urge that a new sub-section be added to the pending legislation (to §216 of S.503 and to §301 of S.865) to provide:

"Any person who, under false pretenses, obtains medical information concerning an individual from a health care provider and who knowingly and willfully sells or transfers such information for profit or monetary gain, shall be guilty of a felony and upon conviction shall be fined not more than \$30,000 or imprisoned for not less than two nor more than five years, or both."

The Denver Grand Jury made this same recommendation (that theft of medical records be made a federal felony) in its report to the U.S. Privacy Protection Study Commission, June 8, 1976.

V. PATIENT ACCESS TO THEIR OWN MEDICAL RECORDS: RIGHTS OF MINORS

I believe that both S.503 and S.865 are properly clear and unequivocal in recognizing the right of the patient to have access to his own medical information. I would urge that those provisions not be watered down.

S.503 (§§ 203, 205 and 206) uses age 12 as the age at which a person attains access and authorization rights to his medical records, whereas S.865 (§310) uses the more traditional age of 18 years. My own recommendation is that a proper compromise would be 15 years of age. Such a compromise would extend the medical information rights to those generally of high school age, while placing those rights

with the parents or guardians for those generally of junior high school age and younger.

VI. GOVERNMENT ACCESS PROVISIONS OF THE PROPOSED LEGISLATION

It is my strong belief that the government access provisions of each bill, as they relate to law enforcement, would not impede criminal investigations. Generally speaking, in a criminal investigation, most often the medical records sought are those of the victim. Each bill gives the patient or his representative authority to consent to access to the medical records by the appropriate law enforcement authorities. In those cases where the suspect's medical records are the focus of the investigation, the notification provisions are certainly reasonable.

However, I strongly urge that sub-section (1) of §218 of S.503 and sub-section (1) of §212 of S.865 be deleted. Those two sub-sections, which are identical, provide that medical information concerning an individual obtained from a health care provider pursuant to a subpoena issued under the authority of a grand jury "shall be returned and actually presented to the grand jury." Such a provision is unrealistic.

First, in the real world, health care providers have no desire to expend the time required to go personally to the grand jury to present records which can just as securely and more expeditiously be presented to a grand jury investigator pursuant to a subpoena.

Second, such a procedure would unnecessarily utilize the limited time of the grand jury in a mechanical exercise. Third, such a provision would encourage prosecutors to utilize search warrants rather than subpoenas -- a procedure which is potentially more disruptive to the health care provider than the service of a subpoena. Finally, even without these sub-sections (1), which I urge be deleted, any health care provider would always be entitled to proceed formally and to actually present the medical records to the sitting grand jury, if the provider elects to do so.

VII. EFFECTIVE DATE

Section 221 of S.503 provides for an effective date 180 days after enactment, while Section 311 of S.865 provides for an effective date after enactment of one year as to some sections and two years as to others.

I would urge that the effective date contained in S.503 (180 days after enactment) be utilized in the legislation the committee approves. The invasion of privacy of medical records is much too great a problem and much too important an issue to be delayed more than six months after enactment. Citizens have already waited too long for this protection.

DALE TOOLFY
DISTRICT ATTORNEY
2ND JUDICIAL DISTRICT
DENVER, COLORADO

EDUCATION:

B.A., L.L.B. University of Colorado, 1957.

BAR ADMISSIONS:

Admitted to Practice in Colorado; United States District Court; U.S. 5th and 10th Circuit Courts of Appeals. Member, American, Colorado and Denver Bar Associations.

PROFESSIONAL EXPERIENCE:

Elected Denver District Attorney, November, 1972; Re-elected without Opposition to Second Term in November, 1976; Past President, Colorado District Attorneys Council (Association); Chairman, White Collar Crime National Strategy Committee of the National District Attorneys Association; Officer and Director, NDAA; Commissioner, National Commission on Victim/Witness Assistance; Chairman, Medicaid/Medicare Fraud Committee and Business Opportunity Fraud Task Force, NDAA; Member, Grand Jury and Prosecution Function Committees of the American Bar Association; Denver Anti-Crime Council; Past Chairman, Governor's Task Force on Medicaid/Medicare Fraud; Served as Member of Colorado Supreme Court Grand Jury Rules Committee and as Colorado's Member on the Federal Legislative Advisory Committee of the American Bar Association; Admitted to the Bar at Age 23, Associated with the Denver Firm of Dawson, Nagel, Sherman and Howard, and then a Partner in the Denver Firm of Van Cise, Freeman, Tooley and McClearn until Elected Denver District Attorney; Director, Drug Abuse Council, Inc.

OTHER ACTIVITIES:

Member, Denver Community Corrections Board; Director, Boys Clubs of Denver, Inc.; Past President, Denver Area C.U. Alumni Association; Director, Opportunity Industrialization Center; Director, CAP (Citizens Appreciate Police, Inc.)

PROTECTED - CONFIDENTIAL

CASE DIGEST

The captioned subject was hospitalized in the psychiatric ward with a diagnosis of psychotic depressive reaction. The purpose of this investigation will be to delve into our medical history for any previous psychological problems.

SUMMARY

The captioned subject is of [REDACTED] descent and does not speak English. Due to this language barrier she was first examined by Dr. [REDACTED], and he was unable to communicate with her. Hence she was referred to Dr. [REDACTED], who is a noted [REDACTED] psychiatrist. The patient's history reveals that in [REDACTED] her spouse deserted her and this brought on the psychotic depressive reaction. According to our medical sources there was no indication INVESTIGATION that she has a pre-existing psychological disorder.

EXHIBIT "A"

Page 3

1 [REDACTED] Hospital

2 [REDACTED]
3
4 Through our medical sources at this hospital we screened files
5 and discovered the following:

6 Patient: [REDACTED]

7 Address: [REDACTED]
8 [REDACTED]
9 [REDACTED]

10 Occupation: [REDACTED]
11 [REDACTED]

12 Insurance Applicant: Blue Cross, [REDACTED]
13 [REDACTED]
14 [REDACTED]

15 Attending Physician: Dr. [REDACTED]
16 [REDACTED]
17 [REDACTED]
18 [REDACTED]
19 [REDACTED]

20 Date of Admission: [REDACTED]

21 Date of Discharge: [REDACTED]
22 [REDACTED]

23 Admitting Diagnosis: Gastro enteritis
24

25 According to our medical sources the chart pertaining to this
26 patient's history as well as her treatment was relatively scant.
27 There was mention that Mrs. [REDACTED] did not speak English and was
28 admitted for acute symptoms of gastro enteritis. There was no
29 past medical history recorded due to the language problem, and
30 eventually a psychiatrist identified as Dr. [REDACTED] was called
31 in.
32

33 Our sources told us that Dr. [REDACTED] speaks [REDACTED] fluently
34 and due to the patient's emotional problems resulting from the
35 loss of her husband, he took over the case. All of the tests
36 including upper GI series, were negative relevant to peptic
37 ulcer disease, etc.
38
39

40 Final Diagnosis: Gastro enteritis & psychotic depressive reaction.
41

Page 4

Through our medical sources here we determined that the patient was admitted on [REDACTED] and discharged on [REDACTED]. She was under the care of Dr. [REDACTED].

The total bill was \$3,991.36 and this was paid in 2 installments by Blue Cross of [REDACTED]. the first payment was received on [REDACTED] in the amount of \$2987.50 and the second installment on [REDACTED] in the amount of \$941.75.

Once again our medical sources told us that the hospital chart pertaining to her history as well as her course of treatment was relatively scant. We might add that under the California statutes psychiatrists will not give out information on a patient's treatment even with an authorization. If they do so they can be subjected to a \$500 fine.

In any event the patient's history revealed that she was a [REDACTED] American and did not speak English. She was working as an [REDACTED] for [REDACTED], anxiously awaiting the arrival of her spouse, namely [REDACTED]. However he wrote a Dear John letter explaining that he was going to leave her when he came stateside. Since Mrs. [REDACTED] believes in the ancient customs of the [REDACTED], she lost face and went into a psychotic depressive state of mind.

This condition began in August of [REDACTED] and through psychotherapy and chemotherapy her condition was somewhat improved when she was discharged on [REDACTED] to be followed by Dr. [REDACTED] on an office visit basis. Her past medical history was relatively blank. There was no indication of any previous psychological disorders and once again the cause of her problems stems around the fact that her husband decided to leave her for another woman when he comes stateside.

Final Diagnosis: Psychotic depressive reaction.

Dr

Page 5

Qualifications: Born: [REDACTED]
 Graduated: [REDACTED]
 Specialty: [REDACTED]
 Member: AMA

According to our sources there was no indication that the doctor was licensed in the state of California, however this could be a typographical error or perhaps the background file on the doctor erroneously did not list the year he was licensed. In any event there was no indication that he is licensed to practice medicine in the state of California.

Residency: [REDACTED]
 [REDACTED]
 [REDACTED]

Through our medical sources we discovered that [REDACTED] first sought medical treatment with Dr. [REDACTED] on [REDACTED]. According to our sources she was referred to the doctor by [REDACTED]. It seems that Dr. [REDACTED] examines quite a few of the personnel at [REDACTED].

When the doctor first treated the patient there was indications of symptoms relevant to an acute gastro enteritis. Since the patient did not speak English it was very difficult for the doctor to communicate and all he could do was to treat the symptoms of gastro intestinal problems accordingly.

Eventually [REDACTED] roommate, namely [REDACTED], was called in as an interpreter.

The doctor discovered that [REDACTED] was happily married to [REDACTED] in [REDACTED] and he was due to report for duty in the [REDACTED] area at the [REDACTED] Base very soon. Apparently he wrote [REDACTED] a Dear John letter and decided that when he came stateside he would divorce her. Since your subject is a Japanese descent and believes all the ancient customs, this caused her to lose face. Hence her condition seemed to deteriorate rather rapidly after the letter was received, some time in August 61 [REDACTED].

Page 6

The doctor had the patient admitted to the [redacted] Hospital for treatment of a gastric disorder and when all the tests came back normal he called in a psychiatrist, namely Dr. [redacted] for his opinion. Incidentally Dr. [redacted] speaks fluent Japanese. The psychiatrist affirmed that her mental status was centered around the fact that her husband decided to leave her and has caused her to lose face. The last time your subject was treated by Dr. [redacted] was on [redacted]

Dr. [redacted]

Qualifications: Born: [redacted]
 Graduated: [redacted]
 Licensed: [redacted]
 Specialty: Psychiatry
 Member: AMA
 Interned: [redacted]

Residency: [redacted]

At this time we must point out that all psychiatric records are highly confidential and for this reason it is rather difficult to obtain their contents in the state of California, even through our medical sources. In any event we were able to determine that [redacted] has not been treated by Dr. [redacted] for a few months. In essence her diagnosis of psychotic depressive reaction was brought on by the fact that her husband wrote her a Dear John letter advising her that when he came stateside in [redacted] he would no longer desire that she be his wife.

As far as the doctor could determine, there did not appear to be a pre-existing psychological disorder, and the patient was never hospitalized in the past.

At this point we decided to follow up with the lead that your subject's spouse was in the Armed Forces and perhaps she was treated at the Military Installation or perhaps some other hospital in that area.

Page 7

1 ~~XXXXXXXXXX~~ Base
 2 ~~XXXXXXXXXX~~
 3 ~~XXXXXXXXXX~~

4 Checking files at the Base Locator's office, we determined the
 5 following:
 6 ~~XXXXXXXXXX~~
 7 ~~XXXXXXXXXX~~
 8 ~~XXXXXXXXXX~~

9 Serial ~~XXXXXXXXXX~~
 10 ~~XXXXXXXXXX~~

11 Present Location: ~~XXXXXXXXXX~~
 12 ~~XXXXXXXXXX~~

13 Forecasted Location: ~~XXXXXXXXXX~~
 14 ~~XXXXXXXXXX~~
 15 ~~XXXXXXXXXX~~

16 His orders indicate that he is due to report in for duty here at
 17 the ~~XXXXXXXXXX~~ Base in ~~XXXXXXXXXX~~
 18 ~~XXXXXXXXXX~~
 19 ~~XXXXXXXXXX~~
 20 ~~XXXXXXXXXX~~

21 Through our sources at ~~XXXXXXXXXX~~ we were able to determine that there
 22 was a chart on ~~XXXXXXXXXX~~. Our medical sources pulled this file for
 23 any mention of psychological disorders prior to April of ~~XXXX~~. The
 24 only time she was ever hospitalized was in October of ~~XXXX~~, and this
 25 was for a tonsil abscess.
 26 ~~XXXXXXXXXX~~

27 Our medical sources told us that there was no indication of my
 28 previous psychological disorder and with the exception of this
 29 one hospital confinement in October of ~~XXXX~~, there was no other
 30 medical information on your subject.
 31 ~~XXXXXXXXXX~~

32 REMARKS: As the reader can see, due to the subject's language
 33 problem, her attending physician was unable to obtain a concise
 34 and complete past medical history. However through the use of
 35 the ~~XXXXXXXXXX~~ psychiatrist, namely Dr. ~~XXXX~~, they
 36 were able to successfully treat the patient for a psychotic
 37 depressive reaction. This condition was brought on by the
 38 fact that her husband, ~~XXXX~~, decided to leave her for
 39 another woman and notified her of his intentions in August
 40 of ~~XXXX~~
 41 ~~XXXXXXXXXX~~

Page 8

1 Ever since that time her condition deteriorated and eventually
2 she was hospitalized for the aforementioned psychotic depres-
3 sive reaction under Dr. [REDACTED] care.
4

5 Her military medical records did not reveal any previous
6 existing psychotic condition and the only time she was ever
7 hospitalized according to military files was in October of
8 [REDACTED] for a tonsil abscess.
9

10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41

PRIVILEGED - CONFIDENTIAL

CASE DIGEST

The captioned subject was severely injured in a ~~blast~~ blast occurring ~~at~~ at a location of ~~in the city of~~ in the city of ~~As the reader did not know of the date of the incident or the nature of this claim, we were to develop all facts pertaining to this accident as well as medical information, employment, insurance coverage, and general background on the subject.~~

SUMMARY

~~was in charge of the~~ ~~at the time of this accident.~~
He was injured within the course and scope of his employment when ~~exploded in his face~~ exploded in his face on the above captioned date. At the time, your subject was being assisted by ~~who were also severely injured.~~ who were also severely injured. ~~had applied for and is receiving extensive benefits through state, federal and private INVESTIGATION insurance for total disability.~~ His most serious injuries pertain to loss of vision. In this regard, ~~is considered to be legally blind. Details follow.~~

For the reader's information, we attempted to utilize the patient authorization provided us in order to obtain complete hospital and Doctor records for the subject but succeeded in creating what best can be described as a total impasse with regard to both the hospital and Doctor in this matter. Initially, we were told by medical records that the chart for ~~was out of file and~~ was out of file and either the patient had been admitted or his record was misfiled or checked out. After waiting patiently for this document to be located, we re-inquired approximately one week later and were again told that the chart for ~~was not in the record room.~~ was not in the record room. No one seemed to have the vaguest idea of where this document had been stashed as the patient was not currently in the hospital at

EXHIBIT "B"

A REPORT IS CONFIDENTIAL. IT IS INTENDED FOR YOUR USE ONLY. IT SHOULD NOT BE DISPLAYED BY YOU TO ANY AUTHORIZED PERSON AND IS INTENDED TO ASSIST YOU IN EVALUATING THE MATTER UNDER CONSIDERATION

~~CONFIDENTIAL~~ - 2

1 least to the best of their knowledge which seemed to be quite limited.

2
3 In the matter of obtaining records, we are customarily requested
4 by clients to determine medical information without authorization
5 and have managed to develop very good channels over the years for
6 this type of procurement. So, having had little success in even
7 locating this record, much less obtaining copies, we decided to
8 take advantage of sources at ~~Memorial Hospital~~ who proceeded to
9 find ~~Dr. [redacted]~~ chart which incidentally is in three volumes,
10 in the eye clinic where it had been checked out by his attending
11 physician, ~~Dr. [redacted]~~, a staff ophthalmologists.

12
13 With this information in hand, we proceeded to the eye clinic with
14 our patient authorization and attempted once again to obtain Dr.
15 ~~Dr. [redacted]~~ records for review. At this time, we were asked to
16 leave a copy of the authorization and the records would be photo-
17 stated within a day or two, whereupon we could pick them up at
18 our convenience.

19
20 This done, we once again proceeded to the eye clinic four days
21 later at which time we were given a photostat of Doctor's letter
22 dated ~~11/11/54~~ directed to your attention, ~~Dr. [redacted]~~
23 ~~Dr. [redacted]~~. Needless to say, as we already had a copy of
24 this letter, this information was not only redundant but is very
25 limited in scope and contains no history of the patient's actual
26 eye injury.

27
28 Attempting to obtain any additional information proved to be futile
29 and we were simply told that this was all Doctor was prepared to
30 release at this time and any additional information would have to
31 be requested at a later date. Somewhat perturbed at this lack of
32 cooperation on both the part of the Doctor and this hospital, we
33 decided to quit wasting time to obtain records legitimately and
34 once again directed our sources to pull the chart on the sly and
35 photograph all relevant parts.

36
37 This was done by a surgery intern who works for us and we were
38 given copies of the discharge summary, patient histories, and
39 operative procedures for 13 separate admissions involving ~~Dr. [redacted]~~
40 ~~Dr. [redacted]~~ which for some reason Dr. ~~Dr. [redacted]~~ has decided to keep out
41 of the medical records room and under lock and key in his own
possession.

~~CONFIDENTIAL~~
THIS REPORT IS CONFIDENTIAL. IT IS INTENDED FOR YOUR USE ONLY. IT SHOULD NOT BE DISPLAYED BY YOU TO ANY UNAUTHORIZED PERSON AND IS INTENDED TO ASSIST YOU IN EVALUATING THE MATTER UNDER CONSIDERATION.

Photostats of this hospital information is attached to our report.

Additionally, we are attaching photocopies of local newspaper coverage for this ~~accident~~ accident which took place ~~and~~ and severely injured ~~the patient~~.

We are summarizing the facts of our investigation in narrative form for the reader's convenience in reading as follows:

~~My patient~~ underwent almost immediately enucleation (removal) of his right eye at ~~the time of the accident~~. Additionally, your subject sustained a severe hearing loss in his right ear and partial loss in his left ear, loss of his right hand at the wrist, and amputation of two fingers on his left hand. The vision in his left eye is considerably impaired and from a review of Dr. ~~My patient's~~ records, our source reports the following evaluation dated ~~the date of the accident~~.

Currently existing vision in left eye vasclates from 20/25 down to as low as finger counting at two or three feet. This is due to various problems, particularly graft rejection and secondary glaucoma. He is currently under regular maintenance for secondary glaucoma with uncertain outcome.

The patient is in my opinion totally disabled relevant to any regular occupation. However, if the secondary glaucoma process can be controlled, it is possible at some time in the futuro he can live a normal life and possibly seek gainful occupation.

~~THIS REPORT IS CONFIDENTIAL. IT IS INTENDED FOR YOUR USE ONLY. IT SHOULD NOT BE DISCLOSED BY YOU TO ANY AUTHORIZED PERSON AND IS INTENDED TO ASSIST YOU IN EVALUATING THE MATTER UNDER CONSIDERATION.~~



HOUSE BILL NO. 1110. BY REPRESENTATIVES Dodge, DeFilippo, DeHerrera, DeNier, Durham, Erickson, Kopel, Lillpop, Taylor, Theos, and Younglund; also SENATORS Cole, Meiklejohn, Woodard, and Zakhem.

CONCERNING THE "COLORADO CRIMINAL CODE", AND MAKING MISCELLANEOUS AMENDMENTS THERETO.

Be it enacted by the General Assembly of the State of Colorado:

SECTION 2. 18-1-901 (3) (r), Colorado Revised Statutes 1973, 1978 Repl. Vol., is amended to read:

18-1-901. Definitions. (3) (r) "Thing of value" includes real property, tangible and intangible personal property, contract rights, choses in action, services, CONFIDENTIAL INFORMATION, MEDICAL RECORDS INFORMATION, and any rights or use or enjoyment connected therewith.

SECTION 6. Part 4 of article 4 of title 18, Colorado Revised Statutes 1973, 1978 Repl. Vol., is amended BY THE ADDITION OF A NEW SECTION to read:

18-4-412. Theft of medical records or medical information - penalty. (1) Any person who, without proper authorization, knowingly obtains a medical record or medical information with the intent to appropriate the medical record or medical information to his own use or to the use of another, who steals or discloses to an unauthorized person a medical record or medical information, or who, without authority, makes or causes to be made a copy of a medical record or medical information commits theft of a medical record or medical information.

(2) As used in this section:

(a) "Medical record" means the written or graphic documentation, sound recording, or computer record of services pertaining to medical and health care which are performed at the direction of a physician or other licensed health care provider on behalf of a patient by physicians, dentists, nurses, technicians, or other health care personnel. "Medical record" includes such diagnostic documentation as X rays, electrocardiograms, electroencephalograms, and other test results.

EXHIBIT "C"

(b) "Medical information" means any information contained in the medical record or any information pertaining to the medical and health care services performed at the direction of a physician or other licensed health care provider which is protected by the physician-patient privilege established by section 13-90-107 (1) (d), C.R.S. 1973.

(c) "Proper authorization" means a written authorization signed by the patient or his duly designated representative or an appropriate order of court or authorized possession pursuant to law or regulation for claims processing, possession for medical audit or quality assurance purposes, possession by a consulting physician to the patient, or possession by hospital personnel for record-keeping and billing purposes.

(d) "Copy" means any facsimile, replica, photograph, sound recording, magnetic or electronic recording, or other reproduction of a medical record and any note, drawing, or sketch made of or from a medical record.

(3) Theft of a medical record or medical information is a class 5 felony.

SECTION 9. Part 1 of article 8 of title 18, Colorado Revised Statutes 1973, 1978 Repl. Vol., is amended BY THE ADDITION OF A NEW SECTION to read:

18-8-115. Duty to report a crime. It is the duty of every corporation or person who has reasonable grounds to believe that a crime has been committed to report promptly the suspected crime to law enforcement authorities. When acting in good faith, such corporation or person shall be immune from any civil liability for such reporting. This duty shall exist notwithstanding any other provision of law to the contrary; except that this section shall not require disclosure of any communication privileged by law.

SECTION 12. Effective date - applicability. This act shall take effect July 1, 1979, and shall apply to offenses alleged to have been committed on or after said date.

SECTION 13. Safety clause. The general assembly hereby finds, determines, and declares that this act is necessary for the immediate preservation of the public peace, health, and safety.

APPROVED - June 22, 1979

/s/ Richard D. Lamm
 Richard D. Lamm
 GOVERNOR OF THE STATE OF COLORADO

F. LETTER FROM EDMUND B. RICE, LEGISLATIVE REPRESENTATIVE,
AMERICAN HOSPITAL ASSOCIATION, SUBMITTING STATEMENT ON
PRIVACY OF MEDICAL RECORDS LEGISLATION



AMERICAN HOSPITAL ASSOCIATION

444 NORTH CAPITOL STREET, N.W., SUITE 500, WASHINGTON, D.C. 20001 TELEPHONE 202-638-1100
WASHINGTON OFFICE

November 27, 1979

Honorable Richardson Preyer, M.C.
Chairman, Subcommittee on Government
Information and Individual Rights
Committee on Government Operations
House of Representatives
Washington, D.C. 20515

Dear Mr. Chairman:

Submitted herewith are copies of the American Hospital Association's testimony on H.R.2979 and H.R.3444, for inclusion in the written hearing record on this legislation.

Sincerely,

Edmund B. Rice
Legislative Representative

Encl.

Statement of the American Hospital Association

TO THE SUBCOMMITTEE ON GOVERNMENT INFORMATION
AND INDIVIDUAL RIGHTS
OF THE
HOUSE COMMITTEE ON GOVERNMENT OPERATIONS
ON H.R.2979 AND H.R.3444,
PROPOSALS TO PROTECT THE PRIVACY OF MEDICAL RECORDS

November 26, 1979



Headquarters
American Hospital Association
840 N. Lake Shore Drive
Chicago, Illinois 60611

Washington Office
444 N. Capital Street N.W.
Suite 500
Washington, D. C. 20001

For Further Information Contact:

Leo J. Gehrig, M.D., 202/638-1100
Edmund B. Rice, 202/638-1100



STATEMENT OF THE AMERICAN HOSPITAL ASSOCIATION
TO THE SUBCOMMITTEE ON GOVERNMENT INFORMATION
AND INDIVIDUAL RIGHTS
OF THE
HOUSE COMMITTEE ON GOVERNMENT OPERATIONS
ON H.R.2979 AND H.R.3444,
PROPOSALS TO PROTECT THE PRIVACY OF MEDICAL RECORDS

November 26, 1979

The American Hospital Association, which represents over 6,100 hospitals, long-term care facilities, mental health institutions, hospital schools of nursing, and over 30,000 personal members, is pleased to present its views and recommendations on the proposals before this Subcommittee to protect the privacy of medical care records.

In 1977, the Privacy Protection Study Commission presented its final report to the President and to Congress. One chapter of that report listed fourteen recommendations regarding the record-keeping practices of medical care providers. Eight of the recommendations reflect in large measure the basic privacy protection principles endorsed by the American Hospital Association. The AHA is in agreement with the Commission's conclusion that an effective privacy protection policy should have three concurrent objectives: to minimize intrusiveness, to maximize fairness, and to create legitimate expectations of confidentiality.

Our sole point of disagreement pertains to the need for legislation at the federal level in the area of medical records privacy. We believe that such legislation is neither necessary nor desirable.

Our comments will specifically examine existing laws and policies governing access to medical information and compare these laws and policies to the issues involved in a federal approach to privacy

protection. In addition, we will comment on specific provisions of H.R.2979 and H.R.3444.

PRIVACY PROTECTION IN THE MEDICAL CARE SETTING

The right to privacy is not absolute. Third parties can gain legitimate access to the medical records by obtaining the written consent of patients, and the hospital is obliged, with few exceptions, to comply with properly executed authorizations. Third parties also may gain access by virtue of legal authority or when public health considerations supercede a patient's right to privacy. Concern has been expressed, however, over the discretionary powers of the hospital to determine who may have access to the contents of medical records and to define the information that may be disclosed.

The AHA does not concur with the conclusion that federal legislation is needed to deal with legitimate interests and needs for medical records disclosure and the patient's desire and rights to privacy. Our position is based on the following reasons, which are elaborated below:

- In practice, medical and hospital personnel respect the confidentiality of medical records;
- Voluntary accreditation standards for hospitals prescribe access and confidentiality practices for medical records administration;
- Statutes and licensing regulations in most states protect the confidentiality of medical records;
- Court decisions have afforded complete protection to patients through the common law right of privacy, and courts have imputed an implied contract of confidentiality to medical records;
- Federal regulation would interfere needlessly with legitimate state public policy interests; and

- HEW's experience with medical information regulation demonstrates that the Department could not implement such regulations without substantially increasing governmental intrusiveness and costs.

Hospital Practice

Hospitals, their governing boards, and medical staffs have historically developed and implemented policies governing access to patient care records. Moreover, a number of state hospital associations and the AHA have encouraged such policies, and we have included with this statement a copy of AHA's Guidelines On Access To Patient Care Records.

A principle of AHA policy is that every hospital is responsible for establishing and implementing security measures that reasonably safeguard medical records and their contents against loss, defacement, tampering, unauthorized disclosures, and use by unauthorized persons. Despite recently publicized instances of the use of fraudulent means to obtain unauthorized access to medical records, it is our opinion that federal legislation--even with provisions establishing criminal sanctions for such activity--would never totally prevent such occurrences. While statutes may deter some persons from committing theft or fraud, these practices will continue if the perceived benefits of unauthorized access are great enough. It must be acknowledged that every regrettable antisocial act does not warrant a legislative remedy.

Existing state laws impose criminal penalties for theft by false representation. In some states, specific measures pertaining to medical records policies and procedures are pending. The AHA supports such state laws, but it is our position that unlawful breaches of privacy will most effectively be reduced through the dissemination of information and guidelines to aid and encourage the improvement of each hospital's security measures. State and voluntary approaches allow individual hospitals flexibility to adopt those policies and procedures that do not defeat the primary purpose for which the medical record is maintained--accessible and accurate information for the care of patients.

The Privacy Protection Study Commission identified insurance carriers and governmental agencies, both federal and state, as the most frequent requestors of patient-identifiable medical record information. In most hospitals, disclosure to federal and state agencies without authorization (other than a blanket authorization executed by the beneficiary upon first enrolling in a governmental program) comprise more than 50 percent of all disclosures. Thus, regulatory authority exists to address a major portion of the concerns about disclosure through the establishment of reasonable limitations on requests for medical information made by governmental agencies. Imposing additional federal regulations on hospitals would not address the problem as effectively as cooperative work by third parties to develop more carefully justified and less intrusive requests for patient-identifiable information.

Further, it must be noted that individual hospital policies have the advantage of adaptability in unforeseen or unique local circumstances. Although most legislative proposals have included provisions for unauthorized disclosures in "compelling circumstances," uncertainty about how a federal standard would be interpreted in individual circumstances could chill the exercise of this necessary local discretion.

Voluntary Accreditation and Standards

The Joint Commission on Accreditation of Hospitals (JCAH) includes standards for the maintenance and protection of medical records in its survey criteria. These standards address the hospital's responsibility to safeguard the security and the confidentiality of the record, policies on external release of medical information, and on internal use of the record.

For example, JCAH standards require that the hospital's medical staff bylaws include a statement of conditions under which members of the medical staff may use medical records for bona fide study. The hospital-based researcher is aware of the serious consequences of not adhering to hospital and medical staff policy.

By contrast, privacy protection policies relating to government research contracts and subcontracts are often obscure and ineffective. As a result, AHA and state hospital associations have reviewed external research requests involving the use of hospital records and have provided guidelines to hospitals in this regard. These guidelines assist the institutions to evaluate (a) the suitability of the medical record for the proposed purpose, (b) limitations under which the medical record information is to be collected, (c) the adequacy of the requestor's commitments to safeguard patient privacy, and (d) limitations on further use or redisclosure of the medical information. Ultimately, it is the medical staff of the hospital which can best determine if the medical record or a designated portion of it is suited for a particular research project. The medical staff and the hospital administration can impartially assess the extent of the privacy incursion potentially created for their patients, and not HEW in potentially conflicting roles as both the major sponsor of such research projects and a regulator of privacy interests.

Since the JCAH adopted voluntary accreditation standards for medical records administration, all JCAH-accredited hospitals have been advised and periodically examined with respect to their obligations in this regard. In addition, through state agency Medicare participation surveys imposing comparable standards, other hospitals are held accountable for these standards. Failure to comply with JCAH standards can lead to a loss of accreditation status which, in turn, can preclude participation in insurance contracts and federal health programs. It also should be noted that compliance surveys by the JCAH do not identify patients whose records have been reviewed.

State Judicial Law

The courts of nearly every state recognize the common law tort of invasion of privacy. This cause of action is available to redress the release of individual medical information to third parties who do not have a legitimate interest or right to the information.

Additionally, the courts have turned to a long-standing legal theory which affords even broader protection than the traditional right to privacy. This theory imputes an implied right of contract or fiduciary duty against unauthorized disclosure between the provider and the patient. Originally articulated in 1851, this doctrine has been affirmed by recent decisions in Alabama, California, Georgia, New York, Ohio, and Pennsylvania.

Similarly, whenever the issue has been presented, state courts have recognized a common law right of access by the patient or his representative to the medical record for legitimate needs and purposes (e.g., additional health care, legal action, or insurance). This right is generally based on the patient's property right in the information contained in the record or on the fiduciary relationship between the provider and the patient. Only in cases of medical contraindication have state courts denied these requests. Among the jurisdictions recently reaffirming this right are the District of Columbia, Illinois, Michigan, New Jersey, New York, Ohio and Oklahoma.

State Statutory Law

Regulations promulgated pursuant to hospital licensing laws in most jurisdictions require that medical information shall be kept confidential and secure from unauthorized access. Failure to comply with such requirements can result in loss or suspension of institutional licensure.

In addition, approximately three-quarters of the states have statutes which govern the evidentiary use of medical records in judicial proceedings. These statutes either limit the admissibility of the record to those situations in which the consent or waiver of the patient has been obtained, or limit the application of the compulsory process of the court to the medical record, or both. These statutes are reflective of the specific regard given to the confidentiality of medical information by the various states.

More recently, states have codified existing common law doctrines. These statutes create a positive duty not to release medical information without authorization, except in specified circumstances. Statutes defining the extent of this duty exist in Hawaii, Mississippi, New York, Rhode Island, and West Virginia, and are pending in other jurisdictions.

Similarly, many states are codifying the patient's right of access to information relative to his health care and treatment. Again, these statutes can generally be viewed as reflections of existing common law doctrines. Connecticut, Massachusetts, Mississippi, New Jersey, and Wisconsin are examples of jurisdictions with access laws. In such states, the number of patients requesting access to their records has been much less than anticipated.

Potential Conflicts Between National and Local Policies

Certain privacy issues are presently the subject of state and local laws which reflect public decisions on matters of health and welfare. Federal pre-emption in the area of medical records privacy would create potential patient care and legal problems for hospitals in accommodating these state and local public policy concerns. Among these are policies dealing with the age of majority, emancipated minors, and the legal protection of the confidentiality of the medical relationship with minors pertaining to venereal disease, pregnancy, drug abuse, alcoholism, rape, and child abuse. A recent serious example of this type of problem is provided by the privacy protection regulations promulgated under the federal alcohol and drug abuse treatment programs. Because the regulations purport to supercede those state laws with which they conflict, a report of child abuse cannot be made under these programs if making the report could lead to the identification of the patient as an alcohol or drug abuser. Only after there is evidence of a direct physical injury traceable to the advising parent (and traceable without reference to his alcohol or drug abuse) can a child abuse report be made.

Pre-emption by the federal government would also interfere with certain medical relationships. Many minors would no longer seek treatment for

some of the above-identified problems since information on such treatment could be disclosed to parents and third parties. This would substantially impair hospital and public health programs designed to address these problems.

Similarly, the federal law, by establishing a national standard for minors and incompetents, could raise conflicts with state consent laws which are based on different standards. Thus, for example, minors capable of consenting to treatment would be required to have the authorization of a parent or guardian to obtain access to their medical records. This type of situation may involve hospitals involuntarily in legal challenges to state consent laws.

HEW's Experience With Medical Information and Privacy Protection

The Department of Health, Education, and Welfare, directly and indirectly, is today the country's largest single collector of patient-identifiable information. This collection occurs through the conduct of biomedical and epidemiological research; administration of health services programs which require record keeping by state agencies; activities of fiscal intermediaries and federal agencies; establishment of data requirements for utilization review and quality assurance programs; funding of grant and contract programs which cause individually identifiable records to be collected, maintained, and audited; and the delegation of authority to state agencies to conduct certification surveys.

The proposals now before Congress would increase HEW's access to patient-identifiable information. Federal surveys for compliance and subsequent investigations present opportunities for unimpeded scrutiny of any and all patient medical records maintained by hospitals participating in Medicare and Medicaid. It would be both ironic and contrary to the intent of the Privacy Commission for a federal medical records privacy program to decrease the patient's expectations of privacy with regard to the program's administering agency. Unlike JCAH surveys for compliance with hospital accreditation standards, HEW would be able to keep, in patient-identifiable form, an account of all medical records reviewed for compliance with personal privacy regulations.

Further, HEW has circumvented Privacy Act guidelines designed to limit the transfer of such information between agencies of the government by declaring the entire Department, consisting of some 300 program offices, to be a single agency. In view of this record, it is very questionable that HEW could be expected to act as an impartial administrator of a privacy protection law pertaining to medical records.

Administration of similar laws by HEW has proven to be both inefficient and costly. Regulations promulgated pursuant to Section 408 of the Drug Abuse Office and Treatment Act of 1972 and Section 333 of the Comprehensive Alcohol Abuse and Alcoholism Prevention Treatment and Rehabilitation Act of 1970, though well intended, were developed without regard to the various sites and conditions of drug and alcohol abuse programs. As a result, many of the regulations defy realistic application in hospital-based programs and have created extra costs for hospitals, primarily due to the need for legal assistance. The inflexibility of centralized administration and regulation is an inherent problem of any federal approach.

Appended to this statement is a monograph prepared by the American Hospital Association which describes the regulatory burden created by the medical record requirements of the Alcohol and Drug Abuse Treatment Laws. Among the conclusions of this report are:

- expansive definitions of coverage have exceeded the intent of the Acts and have caused hospitals to adopt expensive or burdensome record handling policies;
- restrictions on the use of general consents have resulted in hospitals being unable to comply with state public health laws, to fulfill PSRO obligations, and to receive reimbursement from third parties;
- hospitals have had to bear the burden of defending ambiguous HEW regulations in court; and

- hospital medical staffs have been placed at risk in deciding to release information, even if the release of information otherwise conforms to authorization requirements.

The possibility of well-intended, but overzealous regulation is in conflict with the goals of minimum intrusiveness and maximum fairness. The federal approach ignores the valid interests of the patient in deciding whether or not he wishes HEW to have complete access to his medical record for regulatory purposes.

Based on the foregoing, the AHA recommends against the enactment of legislation establishing a federal medical records privacy program. We believe privacy protection requirements should be the responsibility of state legislatures and the private sector. In addition, we believe that the goals of minimal intrusiveness, maximum fairness to all parties, and appropriate expectations of privacy can best be accomplished by the implementation of voluntary standards for compliance.

COMMENTS ON H.R.2979 AND H.R.3444

Despite our opposition to legislation for medical records privacy protection, we are prepared to provide the Subcommittee with specific comments on the pending proposals. We have identified some misconceptions and problems which--should these proposals be enacted--would be deleterious to the operations of health care providers, their ability to deliver health services efficiently and economically, and would not be in the best interests of their patients. Because the following comments cover a wide range of topics, they are somewhat abbreviated. However, the AHA will be pleased to provide more detailed analysis of any of these topics upon request.

Definition and Purpose of the Medical Record

Information on the examination, care, and treatment of individuals is maintained by hospitals in a variety of forms according to the purpose for which the information is used. For example, patient account records contain information on medication given and diagnostic and therapeutic

services utilized. Similarly, certain departmental records relating to patient care are usually maintained separately from other patient medical information. Also, outpatient services frequently keep separate records on referrals from physicians' offices.

The two bills before this Subcommittee include a very broad definition of the information which would be made available for patient inspection and protection from external disclosure. Such broad definitions encompass not only medical records information, but also patient account records, departmental performance studies, hospital incidence reports, and medical staff (e.g., medical audit committee) minutes and records. Many unintended constraints and uncertainties could arise from the use of these definitions, affecting the internal handling of medical and management information, the processing of insurance claims and payments, and the efficacy of utilization review and medical audit activities within hospitals.

We recommend limitation of the scope of any program designed to protect patient access and privacy rights to that information compiled for purposes of documenting the course of illness and treatment, specifically excluding information compiled for purposes of internal hospital management. Hospitals have their own valid interests in protecting management information from unnecessary or unauthorized disclosure, while the patient has no legitimate interest in this information. The purposes of the proposed legislation do not require a program of such broad scope as to include information needed for hospital management, and the potential burden placed on hospital management would result in decreased operating efficiency and increased costs.

Various provisions of these bills require that certain information be added to the medical record. The primary purpose of the medical record, as noted, is to document the course of a patient's treatment during periods of care. Any decisions to include or exclude various items of information should be consistent with this purpose. We do not believe that it serves patient care objectives to require that authorizations and notices be integrated into the record itself.

To ensure clarity and minimal interference with the clinical use of the medical record, we recommend that provisions requiring additions to the record indicate that such additions be made through supplementation of the medical record with the prescribed information.

Further, it is not appropriate that certain authorizations be filed with the medical record at any unspecified time. For example, authorizations obtained at the time of admission, which permit the hospital's business office to determine benefits and to process the bill, are properly a part of the business office records rather than the patient's medical record. Contrary to the legislative intent, a requirement that these authorizations be filed with the medical record would create a need for greater access to the individual record by more personnel than is now necessary. In considering requirements for additions to the medical record file, there must be clear recognition of the purposes for which the medical record is kept and for which authorizations are obtained. Authorizations related to internal management activities should be differentiated from those related to external disclosures, and the former should be excluded from the requirements of these provisions.

A final problem regarding the proposed supplementation of medical records pertains to several aspects of prevailing management practices in hospitals:

- Microfilming of medical records and computer-assisted medical record systems do not allow current authorizations and notations of disclosure to be "added" to the medical record on a day-to-day basis. There must be explicit flexibility to accommodate the use of efficient storage systems;
- While the patient is hospitalized, authorizations are held separately to prevent loss or tampering and are not added to the permanent record until after the patient is discharged. The permissability of this practice should be explicitly authorized in the requirements;

- Psychiatric units frequently separate authorizations and legal documents from the medical record in the interest of management efficiency. Staff in such units have more frequent need to consult such legal documents and consequently maintain them separately. This practice avoids repetitive handling of the medical record and should be recognized as a permissible procedure; and
- Authorizations for disclosure of only departmental records or X-rays are traditionally filed in the appropriate department rather than with the medical record. This practice is more efficient in maintaining the flow of medical information among providers and also minimizes unnecessary access to the entire medical record. It should also be recognized as a permissible practice.

Failure to recognize these types of management practices, which are well accepted, would increase information handling costs, encourage unnecessary access to medical files, and make necessary information flow more difficult. We believe this to be contrary to the intent of the proposed legislation.

Patient Access

It is the position of the American Hospital Association that a person (or his authorized representative) has the right to verify that a hospital has created and is maintaining a medical record pertaining to care or services provided to him by the hospital and, unless medically contraindicated, to inspect the record and receive a copy of it upon payment of reasonable charges for the service. This right is recognized in both bills. However, we believe further clarification of this right is appropriate in the interests of both the patient and the institution.

Under H.R.2979, a facility may require written application for the inspection and copying of a medical record. Such an option is not clear in H.R.3444. We believe it is essential to ensure that requests for inspecting and/or copying of a medical record are free from ambiguity or uncertainty as to the identification of the patient. Accordingly, we recommend specific inclusion of a provision to that effect.

Also, H.R.2979 would require that the Secretary of HEW publish recommended criteria by which medical care facilities could determine whether an individual's inspection of his record might reasonably be expected to cause sufficient harm to outweigh the desirability of access. This presumes HEW is better informed than local medical practitioners concerning various and unique situations which might pertain to an individual's care. We believe such medical decisions are better left to the physician. At the same time, we believe it appropriate to prohibit denials of patient access which are based solely on a history of current nonpayment of hospital or physician bills.

Requests for Correction

We would again point out that both legal and medical interests counsel against direct amendment of the medical record in many cases. Requests for corrections, statements of disagreement, and responses to such statements should appear in the file as supplements to the record rather than as part of the record itself.

Also, we believe that requests for corrections should more specifically be limited to factual information contained in the record. The medical record is not an appropriate forum for statements of opinion on the competence of physicians or institutional personnel. Nor should the hospital be obligated to include unsubstantiated disagreements with professional findings (e.g., x-ray or pathology reports). To require otherwise would diminish the purpose of the medical record as a factual report on the courses of illness and treatment of the individual.

Conditions and Notice of Disclosure

The AHA's guidelines on medical records disclosure emphasize that disclosure for any purpose should be only to properly identified persons and only to the extent necessary to accomplish the purpose for which the disclosure is made. This approach is embodied in Section 104 of H.R.3444. However, the parenthetical exception concerning disclosures to state and federal authorities in this Section could be interpreted to give such authorities unlimited access to medical records. While we believe the intent of the parenthetical exception is to refer to subsequent sections pertaining to access by governmental authorities, the specific intent should be clarified.

The AHA supports the provisions in Section 103 of H.R.3444 which require that an individual be notified of a facility's record keeping practices upon the first provision of services to the individual or upon request. We believe that the provisions of H.R.2979 would be unduly burdensome in this regard. Section 113 of the bill would require notification to an individual whenever one year or more had elapsed since the institution's previous contact with that individual. This would require time-consuming and costly evaluations of records of all patients and would be especially burdensome to hospitals with active emergency rooms and outpatient departments. Even if hospitals chose to provide notice to all patients at each encounter in lieu of searching records for the date of the last contact, the personnel and material costs would be very high. By contrast, the requirements of H.R.3444 would result in substantially lower costs to hospitals. Moreover, another alternative--to require hospitals to post notices describing their record keeping practices in appropriate places (e.g., admitting offices, emergency rooms, outpatient departments)--would entail even less cost and accomplish the same purpose.

The content of the required notice is also problematic. Definition of the precise categories of disclosure and the agencies and persons authorized to receive such disclosures would be difficult and open to varying interpretations. In some states, as many as 75 agencies could be involved under certain circumstances. Hospitals would, in essence,

be obligated to prepare these notices at the risk of civil liability if subsequent administrative or judicial interpretations of the requirements were more expansive. We therefore support the approach of H.R.2979 which would direct the HEW Secretary to prepare a model disclosure notice for the use of hospitals. Additionally, enforcement of this notice requirement should be held in abeyance pending the promulgation of this model notice.

Authorization for Disclosure

H.R.2979, unlike H.R.3444, would require hospitals to ascertain the purpose for which a patient authorized a disclosure. The AHA believes hospitals certainly have an obligation to ensure that an authorization is properly executed; however, it is neither the responsibility nor the concern of any hospital to request information about, or to evaluate, the stated purpose of authorization for disclosure. On the contrary, we believe such a requirement is itself an unwarranted intrusion into personal privacy and could be deemed an intrusion into other protected relationships, such as that between attorney and client. When an individual signs an authorization for disclosure of medical information, it is his or her responsibility and prerogative to determine the purpose for the authorization.

Unauthorized Disclosures

Medical Personnel. Section 122 of H.R.2979 describes permissible use for "consultation" purposes. Although this term is taken from the Privacy Study Commission's report, it is objectionable because it precludes precise interpretation. A narrow construction of this term could unduly limit internal hospital use of the record for legitimate patient care purposes. In any event, it would cast a shadow of uncertainty over existing hospital policies approved by the administrator, governing board, and medical staff.

H.R.3444 is consistent with the AHA's guidelines on this issue. The language approving disclosure to "a health care provider in connection with health services being provided to the individual" and "consistent with accepted medical practice, to the next of kin or persons with whom

the individual has a personal relationship" allows providers to define access policies more clearly and presents less risk of disrupting patient care services.

The provisions in the two bills dealing with hospital personnel contain certain ambiguities. The approach of H.R.3444 ("employees, agents of, or responsible to") is preferable to that of H.R.2979 ("employees") because many activities of the hospital (e.g., utilization review, medical audit, legal assistance) are performed by persons who are not employees within the legal meaning of the term. However, neither proposal adequately addresses the needs of medical school faculty, medical students, and health professional students to have access to medical records pursuant to their academic and clinical study programs. If definitions are strictly construed, such individuals are neither providers, agents, or employees, and the category "responsible to" cannot be definitively interpreted in this regard. We recommend that specific language be incorporated in the appropriate section to assure that medical education activities would not be disrupted by the operation of a privacy protection program.

Health Research. The intent of provisions in both bills for the use of the "institutional review board" established by the Public Health Service to ascertain the merits of proposed research should be clarified. Repeated statements by HEW that this board should be used by hospitals with regard to research have created concerns among hospitals that the Department intends eventually to supercede the rights and procedures established by hospitals and organized medical staffs to perform the same review functions. We believe that a single national standard creates a dangerous potential for abuse.

We believe that hospital and patient interests in protecting the privacy of medical records outweigh any interests of HEW in "coordinating" multihospital projects and receiving information on all (governmentally-and nongovernmentally funded) medical research projects. Individual hospitals must be able to guard the interests of their patients' records. To that end, the medical staffs of nearly all

hospitals involved in research projects have established bylaws on the use of medical records for research and study purposes.

We recommend that the bills be amended to state clearly that the review of proposed disclosures of medical records for research purposes is primarily the responsibility of the individual institution; and that nothing in the bills is intended to create a presumption of compliance with the Act by the use of the "institutional review board."

A second potential problem in the area of health research relates to the transfer of patient-, physician-, or hospital-identifiable information from one (approved) research project to another project not specifically approved. We have previously noted the expansive interpretations of regulations by HEW which permit unrestricted transference of patient-identifiable information among the bureaus and agencies within the Department. AHA policy states that such transfers should be approved by the administrator of the hospital in which the research is being conducted. This approach better safeguards the interests of the individual hospital and its patients from indiscriminate disclosure. We recommend the addition of such a provision to the proposed legislation.

Further, regarding H.R.2979, we believe that provisions for disclosure to properly identified persons for purposes of audit or evaluation related to a research project can be construed too broadly, permitting persons with only an indirect interest in the project to claim a right of access to individual-identifiable data for "audit" purposes. We urge that more stringent limitations be placed on the use of research data for audit and evaluation purposes.

Finally, we believe Section 124 of H.R.2979, directing the Secretary of HEW to describe conditions for disclosure of individual-identifiable research data in compelling circumstances affecting the health or safety of any person or involving imminent danger of serious property damage, is too broad. Under such circumstances, disclosure should be made only

to appropriate public authorities and not to just any individual or group with a colorable interest in the circumstances. To allow broader disclosure guidelines to be promulgated could place a great deal of personal information in the hands of insurance companies, labor unions, and employers. We recommend that appropriate restrictions be placed on any rulemaking authority assigned to the Secretary in this regard.

Health and Safety. We believe the provisions of H.R.3444 are preferable to those of H.R.2979 in governing disclosures made for reasons of health and safety. Our preference is based upon the fact that H.R.3444 gives institutions clearer direction regarding what would be required of them, especially in relation to reporting requirements established under state laws, thereby diminishing the likelihood of inappropriate withholding of medical record information.

Under this heading, we would like to comment on one frequent situation which has not been adequately addressed in these proposals. In eligibility determinations for various insurance or benefit programs, hospitals often must deal with patients who, for a variety of reasons, are unable to communicate an authorization to disclose needed information. Many of these patients, especially the elderly with Medicare and supplementary coverage, have no responsible person designated to make the authorization on their behalf. Hospitals must be able, according to appropriate guidelines (such as those developed by AHA), to make disclosures on behalf of the patient which are necessary for eligibility determinations. We urge that disclosure in this kind of situation be specifically allowed. We do not believe that language allowing disclosure "in compelling circumstances which the facility has in good faith determined will affect the health or safety of the individual" is sufficient to unambiguously address this situation.

Administrative and Judicial Process. To avoid interfering with the ongoing care of patients under active treatment (e.g., radiation therapy), many jurisdictions will accept photocopies of medical records rather than require delivery of the original records to the courts. It should be made clear in these provisions (Sections 130 and 131 of

H.R.2979 and Sections 105(b)(11)-(15) and (20) of H.R.3444) that there is no intention to prohibit this or any other accommodation between the courts and hospitals designed to minimize disruption of hospital operations.

Governmental Authorities. To fully protect the privacy of the individual, the proposed legislation should impose authorization requirements on more than law enforcement agencies, insurance carriers, and judicial officers. The same detailed information should be required of its agents, and state and local government agencies. The AHA recommends that governmental requests for the use of medical record information for use in public health investigation or for investigation, audit, or evaluation purposes under Title V, part B of Title XI, Title XVIII, or Title XIX of the Social Security Act, or under any other program providing payments to, or concerned with the activities of a hospital, be made in writing, or in person, and that the individual authorized to make such requests furnish the hospital with a copy of an appropriate authorization signed by the individual, showing the individual's title and address. With such a requirement, the hospital could more fully inform any patient as to the nature of disclosures made of his record, thus giving continuity to the patient's rights to know of any such actions. The hospital should not be primarily responsible for documenting such disclosures when it is more appropriate for the government to furnish the hospital with a written request explaining its authority for intrusion into the patient's record and the uses which will be made of the information. We believe that unnecessary requests for access would be greatly reduced if more appropriate requirements were placed on governmental agencies.

Assurance Against Unauthorized Use

Several sections of both bills pertaining to unauthorized disclosures would require third-party users of medical information to furnish "adequate" assurances of their intentions. We believe that the word "written" should be added to this requirement. This would give hospitals supportable evidence of the nature of the assurances received, should the propriety of the disclosure subsequently become an issue.

Civil Actions

The AHA approves Section 108 of H.R.3444, which would exempt information compiled by a facility in anticipation of civil litigation from the individual access and corrections provisions. Clearly, to provide otherwise would unlawfully restrict hospitals' access to the courts and interfere with their rights to a fair trial.

Surveys of Compliance

The AHA believes that hospitals should be afforded adequate opportunity to respond to the results of any survey of compliance undertaken pursuant to privacy protection legislation. This requirement is necessitated by the potential effect of survey results on criminal and civil liability actions, as well as adverse publicity which might follow unilateral release of the findings. To ensure an adequate opportunity, we recommend the addition of a provision for advance notice of the survey results to any hospital identified in such a report.

Remedies

Experience has shown that actual damages are very difficult to prove with regard to unauthorized interference with the privacy of medical information. This difficulty has often resulted in extremely high or unreasonably low awards, inasmuch as valuation becomes a subjective matter and actual damages often are confused with punitive damages. For this reason, we recommend that provisions for civil remedies establish a single liquidated damage sum to replace actual damages in civil judgments.

We further believe that a ceiling should be established on general or punitive damages, as is provided in H.R.3444. Most hospitals follow carefully established policies in handling medical records, with the result that few unauthorized disclosures are made as a result of malice or malintent. Punitive damages are sometimes an emotional response by a judge or jury to the alleged actions. Because this response tends to be more extreme against institutions as compared to individuals, we believe a limitation on the amount is appropriate.

Effect on State Laws

Both H.R.2979 and H.R.3444 contain provisions which describe the relationship between the proposed federal law and existing state and local laws. H.R.2979 provides that, with certain categorical exceptions, the federal law would supercede "any State or local laws governing the confidentiality of medical records maintained by medical care facilities to the extent that the records of such facilities are subject to this title." H.R.3444 states that the federal law would override "State and other Federal laws only to the extent that those laws are inconsistent with the provisions of this part."

We believe the latter approach to be preferable. The language of H.R.2979 could restrict the discretion of the states to address needs and problems not covered by the federal legislation. Federal pre-emption should be limited to the scope necessary to effectuate the provisions of the federal law. We do not believe it appropriate or necessary to grant exclusive jurisdiction in this area to the federal government. Our comments in the earlier part of this statement support this position.

Effect on Minors and Incompetents

For reasons given earlier in this statement, we believe it appropriate for federal legislation to defer to the standards established under the laws of each state for the definitions of majority and incompetency. Therefore, we support the approach in Section 103 of H.R.2979 over that of H.R.3444 in this regard.

Continued Applicability of the Act

Section 309 of H.R.3444 provides that, if a facility subject to the proposed act ceases to be a medical care facility, the provisions of the act would continue to apply to medical information formerly maintained by the facility. In regard to this provision, we note the following:

- In some states, there has been no assumption by the state of the responsibility to provide a residual depository for the medical records of defunct health care facilities. In those

states, closed hospitals may have difficulty in arranging for disposal of records, especially if a federal privacy law is applicable to records transferred to attending physicians who do not choose to assume such obligations; and

- Many states and most hospitals have laws and policies respecting the destruction of medical records. AHA guidelines, on which most of these laws and policies are based, state that records may be destroyed after 10 years from the date of termination (except for records of minors) and that certain data should be maintained on a permanent basis. These guidelines have proven widely acceptable and workable. Therefore, we believe it should be made clear that any provision regarding continued applicability of a privacy enactment is not intended to require permanent retention of hospital medical records.

We appreciate the opportunity to comment on these proposals, and we will be happy to respond to any questions which you or the members of the Subcommittee may have.

PROJECT IMPACT MONOGRAPH

SUBJECT: ALCOHOL AND DRUG ABUSE REGULATION

(P.L. 91-616 and P.L. 92-255)

(42 C.F. R. Part 2)

MARCH 28, 1979

PROJECT IMPACT, a program of the American Hospital Association and its Allied Associations, had its genesis in the recent phenomenal growth in government regulation in all areas and at all levels. Following this growth--and not far behind it--was the recognition that regulatory authority was fragmented, jurisdictions overlapping, and the process itself sometimes counter-productive. In addition, it is widely recognized that there is a need for a periodic review of existing regulations to determine their usefulness and efficacy. President Carter asked for such reviews in his Executive Order #12044 and again on October 24, 1978 when he established the Regulatory Council. And Secretary Califano, in September of 1977, announced Operation Common Sense, a 5 year project to recodify and simplify HEW regulations and guidelines with specific emphasis on clarification and elimination of inconsistent and unnecessary requirements.

PROJECT IMPACT is an integral part of AHA's Advocacy Alliance through which AHA and its members conduct an ongoing investigation of specific regulatory problem areas which merit review and comment. In each monograph, specific recommendations for solutions to the problem are presented.

ALCOHOL AND DRUG ABUSE CONFIDENTIALITY REGULATIONS

BACKGROUND

The basic purpose behind the confidentiality requirements of the Federal Alcohol Abuse Act (P.L. 91-616, sec. 333; 42 U.S.C. 4502) and the Drug Abuse Act (P.L. 92-255, sec. 408; 21 U.S.C. 1175) was to encourage alcohol and drug abusers to seek treatment for their conditions without fear of being subjected to harassment of stigmatization, or of being excluded from other opportunities by means of such treatment. Although it was generally believed at the time the legislation was enacted that only formally organized and federally funded alcoholism and drug abuse prevention programs were affected, the regulations apply to any federally assisted hospital that provides alcohol or drug abuse education, training, treatment, rehabilitation, research or referral.

The unanticipated regulatory provisions and the Department of Health, Education and Welfare Office of General Counsel Opinion letters have created a situation in which considerable burdens are placed on hospitals for activities which are time-consuming and expensive. But, much more important, these regulations are often counter-productive to good patient care. One particularly sad feature of the regulations is their relationship to mandatory state child abuse reporting statutes. Because the regulations purport to supercede those state laws with which they conflict, a report of child abuse cannot be made by a program if making the report could lead to the identification of the patient as an alcohol or drug abuser. Only after there is evidence of a direct physical injury traceable to the abusing parent (and traceable without reference to his alcohol or drug abuse) can a child abuse report be made. The regulations which create problems in this and other areas fall into 4 major sections.

I. DEFINITIONS AND USAGE

THE PROBLEM - The basic definitions of "program,"⁽¹⁾ "patient,"⁽²⁾ "abuse prevention function,"⁽³⁾ and "records"⁽⁴⁾ are so broad as to encompass every effort made by a hospital on behalf of a client with an alcohol or drug abuse connection. And every hospital which is not-for-profit (501 (c) (3)) and/or reimbursed by Medicare/Medicaid or other federal programs falls under the jurisdiction of these regulations under the definition of "federally assisted."⁽⁵⁾

RAMIFICATIONS FOR HOSPITALS - The definitions have been so broadly interpreted that records are covered even when:

- A. the hospital has no alcohol or drug abuse program and makes a referral as part of a treatment for a different diagnosis. (6)
- B. the mission of the hospital is wholly unrelated to alcohol and drugs. The patient could be in the hospital for something entirely different (e.g. a broken leg) and there is only a secondary diagnosis of alcohol or drug abuse, or, even more remotely, the history of abuse is only incidental to the reason for admission. (7)

Because the possible burdens incurred for each record covered are so enormous, the breadth of definition is an important factor. The expansiveness of HEW's view of the coverage of the regulation forces hospitals to review every record to ascertain whether the record comes within the regulation. Alternatively, the hospital must store those records which are subject to the regulation separately to guard against unauthorized access. This is a burdensome process both from the standpoint of cost and judgment.

RECOMMENDATIONS - in order to return to the scope of the original intent of the statute and regulations, definitions should be narrowed in the following ways: (11)

"Program" should be redefined to include only formal, organized, alcohol or drug abuse programs.

"Abuse prevention function" should be redefined to exclude simple diagnosis and referral to appropriate treatment programs.

"Diagnosis and treatment" should be redefined to exclude secondary diagnosis of alcohol or drug abuse when the purpose of the original diagnosis was for purposes other than alcohol or drug abuse treatment.

"Federally assisted" should be redefined to eliminate tax-exempt status as a justification for inclusion in coverage by the regulations. This is a dangerous precedent and there is no relationship between the two issues.

II. WRITTEN CONSENT FOR DISCLOSURE

THE PROBLEM - Generally, the regulations provide that no information, including the patient's identity, can be released without the patient's written consent on a specified form which permits the disclosure of specific information for a specific purpose to specific individual for a specific period. (8) HEW does not permit a blanket consent form to be signed at the time of admission. (9)

RAMIFICATIONS FOR HOSPITALS - The written consent requirement is very difficult and often impossible to fulfill. The alcohol or drug abuse client usually leaves treatment or is referred to an appropriate program prior to the time the hospital receives a request for information. By the time that medical records personnel are aware that they are dealing with a record that comes under these regulations, the patient has already left the hospital. Experience has shown that it is next to impossible to get consents from persons who do not maintain permanent addresses, whose reading and writing skills are minimal, or whose debilitated condition is such that they cannot comprehend or respond to the inquiry. The burden to unravel this maze again falls upon the hospital though its contact with the patient may have been minimal. Without a valid consent form, no information can be given to:

- A. third party payors - if the patient will not or cannot execute the consent, the hospital is unreimbursed.⁽¹⁰⁾ When there is actual treatment of a patient for an alcohol or drug abuse problem, the hospital is aware of its risks and will attempt to secure the required informed consent as soon as possible and monitor the situation as carefully as possible. If, however, the patient is admitted and treated for a broken leg, and it is only during the course of the treatment that a secondary diagnosis is made for alcohol or drug abuse (and then a referral for treatment) no one is aware of the confidentiality problem which has been created until after the patient has left the hospital - at which time it is very difficult to get the informed consent signed. If the patient does not sign the form, the hospital cannot receive reimbursement for any of the treatment (including the broken leg). One of our hospitals has estimated that 85% of its admissions are covered by third party payors. Should these regulations be strictly enforced, assuming an average of 1100 inpatient discharges per month and 2200 Emergency Room visits per month, with 1% of these patients coming under these regulations, as much as \$100,000 per year might be uncollectable. Attached is one hospital's elaborate attempts to work out a procedure by which information could be exchanged with a third-party payor. (APPENDIX A)
- B. parents of minors - this prohibition effectively imposes upon the hospital the duty of free services to minors, since most minors will be unable to pay and probably not even legally responsible.⁽¹¹⁾
- C. Professional Services Review Organizations (PSROs) the burden is on the hospital to not only obtain

the consent of the patient for disclosure of the information to the PSRO but also to see that the PSRO abides by the regulations - particularly as to redisclosure. This is a responsibility in which the hospital has no interest and which it is in no position to discharge.⁽¹²⁾

- D. state welfare authorities - the confidentiality requirement is particularly distressing when someone is identified as an alcohol or drug abuser and is also either pregnant or a possible (probable) child abuser. Many states have enacted child abuse laws which provide, in general, (1) the reporting of suspected cases of child abuse to the state authorities, including information on the child and its parents; (2) child protective services which provide immediate protection of the child, non-criminal investigation for verifications of reports of abuse, and rehabilitation services; (3) either family or juvenile court action to remove a child from its home or impose treatment services; and (4) investigations and criminal prosecution, if appropriate.⁽¹³⁾ Because the regulations claim to supercede state law, many problems are created when an alcohol or drug abuser is also identified as a possible child abuser. Without a consent form signed by the patient, state-mandated disclosure of a suspected child abuser to the proper authorities is prohibited, unless a proper, authorizing court order be obtained. However, even with a court order, only "objective" data⁽¹⁵⁾ can be disclosed which would not include any communications by the patient to program personnel. Thus a child may continue to be abused because the regulations prohibit disclosure by program personnel who have been told by the patient that he is abusing the child.

Conflicts also arise between state and federal statutes (to the detriment of patient care) in the case of drug or alcohol addicted newborn infants ("neonatal abusers"). For example, under certain state laws such as in Michigan, children born with symptoms of addiction are considered to be abused children. In such instances, the Public Health Service in certain opinion letters has stated that, because such a child's addiction is accidental, disclosure to the appropriate state authority would not come under the authority of the regulations. However, the child must be identified as Jane or John Doe because the release of the child's real name in a report of abuse can lead to identifying the mother through such public

documents as a birth certificate and thus might lead to the identification of the mother as an abuser. In the view of HEW the abuser status of the mother cannot be revealed even though it may be of social, medical or psychological significance in the treatment of addicted or abused children. In addition, since the referral of an abuser to an alcohol or drug abuse treatment center is sufficient to place the medical records under the confidentiality requirements of the regulations, hospitals have a strong incentive NOT to refer addicted pregnant women for treatment in order to be free to report the birth of a neonatal abuser and effectively treat the child.⁽¹⁶⁾

RECOMMENDATIONS - In third party reimbursement questions, PSRO and child welfare situations, the hospital's only responsibility should be turn over the required information to appropriately identified persons or agencies. The community of interest which exists between these agencies concerned with health care should be assisted by the free exchange of information which improves the ability of each to do its job - not hinders them by involving them in legal maneuvers which produce incentives contrary to aims of health care delivery.

In addition, an upgraded standard consent form should be adopted which would not immediately identify the patient as an abuser and could be used uniformly.

III. PROHIBITION AGAINST "IMPLICIT AND NEGATIVE" DISCLOSURE TO A NONCONFORMING REQUEST

THE PROBLEM - Regulation 213 (e)⁽¹⁷⁾ requires that any request for information which is "non-conforming" (i.e. not an "authorizing court order") be met with a "non-committal response" in order to avoid "implicit and negative disclosure." Thus, the hospital cannot respond to a request (not even a subpoena)⁽¹⁸⁾ and cannot advise the inquirer why it cannot respond. Moreover, the hospital cannot even tell the inquirer the proper procedure to follow to get the information as that would result in a citation of alcohol and drug abuse regulations and would thereby implicitly identify the patient as an abuser.

RAMIFICATIONS FOR HOSPITALS - The hospital must bear the burden of frequent court appearances, often in ancillary proceedings (contempt of court) to defend HEW's position that no direct one can be identified as an alcohol or drug abuser under any circumstances. The hospital is called upon to educate the court and the inquirer on a point in which it has no interest - the record of a present or former patient. The potential costs of such procedures are enormous. One central city hospital on the west coast receives 2-3

subpoenas a month for records covered by these regulations and each subpoena must be met by court appearances by the hospital, as custodian of the records, in attempts to defend the records from disclosure. The hospital is put in a position vis-a-vis the court of being wrong before it starts and having to defend a commitment which is essentially HEW's - not the hospital's. In addition, there is no direction in the regulations as to the point at which the hospital has discharged its responsibilities; e.g. if the hospital is found in contempt of court and ordered to turn over the records, must it appeal? And for how long?

RECOMMENDATIONS - The hospital should be permitted, at the time of the serving of subpoena, to tender the sealed records to the court and place the future burdens regarding appropriate disclosure upon the court system. Then the hospital would not be burdened with the administrative and compliance consequences of the extreme position adopted by HEW.

IV. SITUATIONS NOT OTHERWISE PROVIDED FOR⁽¹⁹⁾

THE PROBLEM - Even if the hospital obtains a valid consent from the patient or if it receives an "authorizing court order" the hospital must be satisfied that consent was freely given, that disclosure is not and will not be harmful to the patient before the hospital can release the information. The hospital must make this judgment. No objective criteria exist to determine if disclosure will truly help in rehabilitation.

RAMIFICATIONS FOR HOSPITALS - In addition to record keeping, administrative and legal responsibilities, the medical records staff of a hospital must also make judgments, presumably at its peril, that release of information will be in the patient's best interest.⁽²⁰⁾ Hospital employees are in no position to examine disclosure requests, research the criteria, and make informed judgments. In many cases, the hospital will have only referred the patient for treatment elsewhere and will not have been in a program relationship with the patient. No provisions exist to protect hospitals from good faith but incorrect determinations.⁽²¹⁾

HEW has failed to explain under what circumstances a hospital may, without liability, refuse to disclose information, even though the patient wants the information disclosed. Such a situation would put the hospital into the position of protecting the patient from himself.

This spectre of government infringement of individual freedom of choice also seems to be in conflict with the statutory intent to preserve individual dignity.

RECOMMENDATIONS - Since the hospital cannot control the myriad of variables which attend treatment for alcohol and drug abuse, it never can be certain that under no circumstances will harm be done by disclosure. The regulation is thus useless and impossible to apply and should be dropped.

FOOTNOTES

1. 42 C.F.R. §2.11 (y)
2. 42 C.F.R. §2.11 (i)
3. 42 C.F.R. §2.11 (k)
4. 42 C.F.R. §2.11 (o)
5. 42 C.F.R. §2.12 (a) (4) and §2.12-1 and §2.12-1(d)
6. 42 C.F.R. §2.11 (k)
7. 42 C.F.R. §2.11 (e) and §2.11(1) and HEW Gen. Counsel Op. 76-72 (October 21, 1976)
8. 42 C.F.R. §2.13 (a) (b) (c), §2.31
9. 42 C.F.R. §2.31 (a)
10. HEW Gen. Counsel Op. 78-11 (March, 1978)
11. 42 C.F.R. §2.15 and HEW Gen. Counsel Op. 76-12 (March 4, 1976)
12. HEW Gen. Counsel Op. 78-11 (March, 1978) and 42 C.F.R. §2.32
13. 42 C.F.R. §2.23 and HEW Gen. Counsel Op. 75-19 (November 14, 1975)
14. 42 C.F.R. §2.23
15. 42 C.F.R. §2.63
16. HEW Gen. Counsel Op. 76-52 (August 23, 1976)
17. 42 C.F.R. §2.13(3)
18. 42 C.F.R. §2.61
19. 42 C.F.R. §2.40
20. HEW Gen. Counsel Op. 76-3 (January 19, 1976)
21. HEW Gen. Counsel Op. 76-3 (January 19, 1976)



AMERICAN
HOSPITAL
ASSOCIATION

GUIDELINES

INSTITUTIONAL POLICIES FOR DISCLOSURE OF MEDICAL RECORD INFORMATION

These guidelines were developed by the American Hospital Association's Advisory Panel on Privacy and Confidentiality of Hospital Medical Records to promote and preserve the confidentiality of hospital medical records and to establish principles and recommendations for appropriate access to them. The principles established in this document supersede those on the use and release of hospital medical record information as contained in the 1972 book published by the Association, Hospital Medical Records: Guidelines for Their Use and the Release of Medical Information (AHA no. 1250M). These guidelines were approved by the AHA Board of Trustees in November 1978. Use of these guidelines is suggested in conjunction with the Association's Statement on Preservation of Medical Records in Health Care Institutions (S003). The Association is also preparing a companion handbook on medical record procedures to correspond with the principles in these guidelines and to replace the 1972 book.

Introduction

Changes in the social and economic environment, accompanied by rapid growth in record-keeping capabilities, have produced an intensive need and demand for more kinds of and more detailed patient and patient care information. Never before have hospitals had to keep so much information to make possible the completion of daily transactions involving patient care and delivery of services. Never before have hospital medical records been subjected to so many demands for their use and disclosure of contents.

The informational upsurge is largely the result of:

- Increasing complexity of medical care associated with the growth in size and variety of professional disciplines involved in the delivery of health care services.
- Wide-scale use of computers in marshaling information, processing information exchange, and creating data banks.
- Increasing mobility of the population, with the consequent increase in the volume of requests for exchange of medical information.
- Expanding informational needs of governmental agencies for planning, administration, evaluation of government programs, and policy-making purposes.
- Progressive growth in the number of third parties* concerned with the patient and his medical record. Many of these third parties are seeking information for proposed uses, such as payment for patient care, that are quite different from the primary purpose for which it was collected.
- Increased government access to patient-identifiable records and increased reporting of personal information to the government.
- Increased incidence of health-related legal actions and proceedings.

* A party other than the patient, the patient's personal representative, the physician, or the hospital.

- Potential misuse of the authorization for disclosure of medical record information.

A searching examination by the American Hospital Association on how best to use and control hospital medical records brought forth contrasting and sometimes conflicting views on how to ensure privacy rights while at the same time recognizing the legitimate interests of third parties. Of concern to the Association is the prevailing tendency of information seekers to disregard or be unaware of the hospital's obligation to respect the right of patients to personal privacy and to treat records pertaining to their care as confidential.

As the first step in striking a proper balance between the personal privacy rights of patients and the informational needs of hospitals and society in general, the American Hospital Association believes that it is essential for hospitals to have a well-defined policy on the use and disclosure of medical information. This policy should limit disclosures to essential purposes, restrict information disclosure to that necessary to accomplish those essential purposes, promote the use of an authorization for disclosure of medical records, and recognize the limitations of the medical record in performing the many services expected of it. However, provision should be made for those instances when nothing less than a full disclosure of the medical record will suffice.

These guidelines have been prepared to assist hospitals in developing policy manuals on the disclosure of medical record information. Following the concepts of policy formation, the guidelines define areas in which decisions are made and establish policies to cover the areas deemed important. Principles established for internal use differ from those established for external use. Recognition also is given to the exceptional situations that may require special handling.

Characteristics of the medical record

The development of policies on disclosure of medical record content must begin with a set of basic principles. These basic principles relate to the characteristics of the medical record:

purpose, content and format, disclosure, ownership, confidentiality, and accessibility of the medical record.

Purpose

The primary purpose of the medical record is to document the course of the patient's illness and treatment during all periods of care, whether as an inpatient or outpatient. The record is important in medical practice. It serves as an instrument for communication among physicians and other professionals contributing to the patient's care and as a basis for planning and evaluating that care.

The secondary purposes of the medical record are:

- To serve as a source for substantiation of the patient care services and treatment provided.
- To provide clinical data of interest to researchers and continuing education programs.
- To meet and support legal and quasi-legal obligations imposed on the hospital and the physician.

Content and format

The medical record is used by practitioners in the management of patient care. Because of this use, the objectives of effective patient care should serve as the basis for determining content, methods of organizing clinical information, desired manner and style of recording, adequacy and timeliness of entries, and justification for exclusion or inclusion of information.

Ownership

Records of the hospital, including medical records maintained for the benefit of the patient, the physician, and the hospital, are regarded as the property of the hospital. Legal counsel should be consulted as to applications of local laws.

Disclosure

Subject to applicable legal provisions, the hospital may restrict removal of medical records from its files or from its premises, determine who may have access to their contents, and define the information that may be disclosed. In fact, state laws or regulations, or the need to preserve the admissibility of records as evidence in judicial proceedings, may mandate that records be removed only for hospital or courtroom purposes.

Confidentiality

The patient has the right to expect that records pertaining to his care will be treated as confidential, and the hospital has the obligation to safeguard his records against unauthorized disclosure.

Accessibility

Medical records should be used within the hospital only by authorized recipients on a need-to-know basis. Responsibility for disclosure of medical record information by the hospital, with or without the authorization of the patient to whom it pertains, should be delegated to hospital personnel who understand the characteristics of the medical record and recognize the occasional situations that require the advice of a medical staff member or the hospital attorney.

Policies for internal disclosure

The hospital shall provide for the security of the medical

record and establish internal policies to provide for their proper use as needed to carry out functions within the hospital. Access to the medical record without the written consent of the patient depends on:

- The authority and responsibility of the hospital or medical staff member or duly appointed committee or panel requesting access.
- The reason for the request.
- The kind of information required.

Policies for internal disclosure of medical record information should be established for various functions within the hospital as described in the following paragraphs.

Governing board and chief executive officer

Legal precedents recognize the right of access by the governing board of the hospital in order to ensure quality of patient care. All hospital policies on the use of the medical record and on disclosure of medical record content should be prepared in consultation with the hospital attorney and are subject to review by the governing board of the hospital.

The chief executive officer has access to all records of patients whenever necessary to carry out his management responsibility. Except when laws or regulations dictate otherwise, the chief executive officer also has the responsibility for final decisions on what medical record disclosures may be made and the circumstances under which disclosures may be made.

Hospital security

It is the responsibility of the hospital to establish and implement security measures that reasonably safeguard both the medical record and its informational content, whether in hard copy, on film, or in computerized form, against loss, defacement, tampering, unauthorized disclosure, and use by unauthorized persons. All officers and employees of the hospital must be made aware of their responsibility in maintaining the confidentiality of medical record information and of the disciplinary actions that may be taken for unauthorized disclosures of patient-identifiable information.

Patient care

Use of a patient's previous medical record, both inpatient and outpatient, by physicians and other health care professionals involved in the care of that patient at the institution maintaining the record does not require the patient's signed authorization because consent to such use is implied. Disclosure of medical information in the event of direct referral or transfer of the patient to another medical care provider does not require the patient's signed authorization. A record should be kept of the information disclosed.

Quality evaluation

Because of its responsibility for determining whether the quality of care provided to all patients is consistent with standards as provided for in the medical staff bylaws and in the requisites for hospital accreditation, the hospital can use medical record information for quality evaluation without the express authorization of the individual patient to whom it pertains. However, all individual patient identification should be excluded from the routine report of such findings and recom-

mendations. When circumstances dictate otherwise, a coded method of identification may be appropriate for internal use.

Education programs

The hospital should establish rules for the use of medical records in hospital-approved education programs for medical and health care professions and should disseminate the rules to the appropriate program directors and instructors, who also must share the responsibility for protecting the confidentiality of the medical records and ensuring the availability of the records for patient care purposes.

Research

The rules of the hospital shall define the extent to which physicians and other health care professional staff in good standing are privileged to use the medical records for bona fide study and research and shall define circumstances that require patient authorization for such use. Anyone using the medical records for bona fide study and research must also share the responsibility for protecting the confidentiality of the medical records and ensuring the availability of the records for patient care purposes.

*Health data systems and data registries**

The hospital, as a provider and user of data resulting from its maintenance of and/or participation in a health data system, shall ensure that reasonable care is taken to:

- Safeguard the privacy rights of persons identified therein.
- Collect and store relevant information.
- Establish standards for accuracy, timeliness, and completeness of data input.
- Obtain and maintain security of confidential data.
- Control unauthorized disclosure in patient-identifiable, physician-identifiable, or hospital-identifiable form.
- Validate statistical data.
- Closely monitor the data system for its continuing adherence to previously agreed upon policies and procedures.

Hospital affairs

Access to the medical record without patient authorization should be provided only on a need-to-know basis in the management of hospital affairs, including that necessary for performing internal administrative tasks, conducting quality assurance programs, receiving legal counsel, planning health services, and surveying hospital-approved programs for accreditation compliance. Staff access to medical records shall be commensurate with a person's responsibility and authority for conducting hospital business. Disclosures of medical record content shall be made only by those suitably trained or qualified to do so.

Policies for external disclosure

The hospital shall establish policies for the disclosure of medical record information to meet the various controls and requests that arise from outside the hospital. Elements to be

considered in policy formulation include:

- Types of requests.
- Kind of information requested.
- Persons, agencies, or organizations authorized to receive information.
- Permission needed for disclosure.
- Conformance to laws, regulations, and other measures in the public interest.
- Establishment of reasonable charges for furnishing copies.

Provision should be made for handling exceptional requests that result in decisions that may constitute additional policies or important modifications of existing policies.

Policies for external disclosure should be established to cover all events usually faced by the hospital as described below.

Authorization for disclosure

The hospital shall respect each patient's expectation that records pertaining to his care will be treated as confidential. Therefore, no hospital should disclose, or be required to disclose, medical record information in patient-identifiable form to a third party without the patient's authorization, unless such disclosure is:

- Pursuant to law or statutory regulations requiring the hospital to report certain information.
- In accordance with compelling circumstances affecting a person's health or safety.
- Permitted under certain circumstances by the hospital in the conduct of biomedical, epidemiologic, or health services research projects.
- Limited to name, date of admission, and general condition, except in those instances when the patient or his authorized representative requests that even this limited information not be released or when laws or regulations (for example, alcohol and drug abuse treatment) forbid the disclosure of this information.

Patient authorization

Written authorizations are a good practice and may be mandated under some regulatory requirements: for example, the Federal Drug and Alcohol Abuse Act.

One of the purposes of a well-drawn authorization for disclosure of medical record information is to indicate to the patient, or person acting on his behalf, what subject matter is being authorized to be disclosed, the person or organization that will receive the information, and any applicable time limit (see pages 7 and 8).

Disclosure limits

The hospital has a responsibility to limit the disclosure of information to only that which is stated on the authorization or required by law and to limit disclosures made without the patient's authorization to only that information permitted or required by law to accomplish the purpose for which the disclosure is made. Whenever disclosure is made pursuant to the

*For further information, see the AHA *Statement on Health Care Data*, AHA catalog no. 5032.

written consent of a patient involved in a drug or alcohol abuse program or treatment function, such disclosure must be accompanied by the following statement: "This information has been disclosed to you from records whose confidentiality is protected by Federal law. Federal regulations prohibit you from making any further redisclosure of it without the specific written consent of the person to whom it pertains."

Record of authorization

The hospital should maintain either the original or copies of the patient's disclosure authorization, which should be made available for examination by the patient.

Careful consideration should be given to keeping a notation of all disclosures to third parties.

Other health care providers

The hospital shall not honor a request from another hospital, a nonstaff physician, or other health care provider for patient-identifiable medical record information unless the request is accompanied by that patient's authorization for disclosure, except under certain conditions warranting immediate disclosure to a properly identified medical care provider or public health officer. Examples are: (1) a showing of compelling circumstances affecting the health or safety of a person or (2) when needed in connection with a direct referral or transfer of the patient from the hospital to another medical care provider.

Third-party contractors

The hospital shall not disclose, without the patient's authorization, information from the patient's medical record pursuant to the hospital's agreement with a government agency or other third-party payer for payment of hospital service charges to authorized beneficiaries or clients of such a program or plan, unless disclosure is:

- Granted by the hospital on behalf of a patient to determine benefits entitlement when the patient is unable to communicate an authorization for disclosure.
- In accordance with provisions of a particular hospital/third-party agreement for inspection of certain portions of a medical record in the performance of claims processing or financial audit.

Insurance carriers

The hospital shall not disclose to an insurance company or insurance plan any patient-identifiable medical record information maintained by the hospital unless the request is accompanied by the patient's authorization for disclosure or by an authorization for disclosure of information necessary to process the insurance claim(s).

Hospital accreditation and licensure surveys

The hospital shall acknowledge the requisites of hospital accreditation and state licensure bodies to review medical records maintained by the hospital only to the extent required or expressly authorized in the performance of their duties to ensure compliance with approved standards or statutory regulations for medical records, provided the reports of such surveys do not directly or indirectly identify any individual patient.

Government programs

The hospital shall recognize requests for access to or reports of

patient-identifiable medical record information for evaluation, audit, or certification purposes by government agencies pursuant to the administration of a government program only to the extent expressly authorized in applicable statutes or regulations, or if the hospital receives an administrative summons expressly authorized in applicable statutes and issued by administrative or executive authority of government or a judicial subpoena or court order. The summons should identify particular record(s) and/or items of information to be made available to the agency.

Evidence and investigation

The hospital should disclose to attorneys, tribunals, members of the court, or government investigation and law enforcement agencies medical record information in patient-identifiable form only if disclosure is authorized by the patient, unless disclosure is compelled by judicial subpoena, court order, properly issued and authorized administrative summons, or as otherwise mandated by law.

Biomedical, epidemiologic, or health services research

The hospital's chief executive officer shall determine whether or not to permit medical records maintained by the hospital to be used by a third party for purposes of conducting biomedical, epidemiologic, health services, or related research and whether or not the patient's authorization is required in accordance with established hospital policy.

The following determinants should be considered in making the decision:

- The importance of the project's purpose outweighs any nominal risk to individual privacy rights.
- The proposed methodology does not violate any limitations under which the medical record information was collected.
- The safeguards are adequate to protect the confidentiality and integrity of the medical record and information therein.
- The further use or redisclosure of any medical record information in patient-identifiable, physician-identifiable, or hospital-identifiable form requires the written consent of the chief executive officer of the hospital, who shall exercise due regard for the rights of others affected.
- The medical records of the hospital are a suitable source of information for the purpose for which they are to be used.
- The third party makes appropriate commitments for safeguarding the patient's privacy, including, in some instances, an agreement to refrain from contacting the patient or others.

Public health laws

The hospital should disclose, without patient authorization, medical record information in patient-identifiable form pursuant to the provisions of state vital statistics laws, which mandate registration of births, deaths, and fetal deaths, and of other public health laws that compel reporting of certain epidemiologic conditions.

School referrals

The hospital should not disclose to administration personnel, teachers, or nurses in the local school system the results of

diagnostic tests on students referred to the hospital by the school system unless such disclosure is authorized by the student's parent(s) or guardian or, if the student is an adult or emancipated minor, by the student.

Employer requests

The hospital should not disclose to an employer any information on an employee who is the subject of a medical record maintained by the hospital without the employee's authorization for disclosure, unless such disclosure is pursuant to any state or local statute(s) providing specific authority for such disclosure.

Policies for disclosure to patients

The American Hospital Association's statement entitled *A Patient's Bill of Rights*^{*} states: "The patient has the right to obtain from his physician complete current information concerning his diagnosis, treatment, and prognosis in terms the patient can be reasonably expected to understand. When it is not medically advisable to give such information to the patient, the information should be made available to an appropriate person in his behalf."

In addition to information available from the physician, the law (statutory or judicial) of most states recognizes a reasonable right of access to medical record information by the patient or his nominee. The patient's right of access in no way abrogates the hospital's property rights in its record and its right to establish reasonable procedures for access to the patient's record. The attending physician should be notified of the patient's request for access to the medical record. Records containing information that might be detrimental to the physical and/or mental health of the patient, as determined by the attending physician, should be released in a form that minimizes any adverse effect on the patient.

When it is known that patient access to medical record information may be medically contraindicated, the hospital may require that a physician or his designee inspect the record and communicate the appropriate information.

Fairness protection

The hospital's record-keeping relationship with the patient on whom it maintains a medical record is that of fairness and protection of confidential information.

- A person has the right to verify that the hospital has created and is maintaining a medical record pertaining to care or services provided to the person by the hospital.
- A patient has the right to find out that a disclosure of his medical record has been made and to whom it has been made, if such information is available.
- A patient has the right to expect the hospital to exercise reasonable care in protecting the confidentiality of the medical records it maintains.
- Unless access is believed by the attending physician to be medically contraindicated, the patient may look at the record of medical care provided, may request a copy upon

payment of reasonable charges for the service, and may request correction or amendment of information.

- A patient's personal representative(s) or duly authorized nominee(s), upon good cause shown by such person(s), may be granted reasonable access to information contained within the patient's medical record.

Development of policy and procedure

The hospital should develop a policy for internal use that sets forth (1) a person's ability to verify whether or not the hospital maintains a medical record of care and services provided to that person and (2) the scope of a patient's right of reasonable access to the record of medical care provided. The policy should encompass existing centralized and departmentalized systems of medical records. Development of the policy and the related procedures should take into consideration:

- The responsibility of the hospital to provide reasonable administrative, technical, and physical safeguards to ensure that records are disclosed only as expressly specified in applicable laws and regulations, in the patient's signed authorization, and in the hospital's written policies and procedures.
- The identification of record systems within the hospital, such as records created and kept on inpatients, outpatients, emergency service patients, home-care patients, and private outpatients referred for diagnostic or therapeutic services.
- The delineation of hospital policy and any regulatory requirements on preservation, retention, and retirement schedules for patient-identifiable records, including those collected and maintained within the various departments of the hospital.
- Measures to provide evidence of all disclosures of medical record information, other than those made during routine use within the hospital, and the retention of such evidence with the record from which the information was disclosed.
- The notification of the attending or responsible physician(s) when a patient requests access to his medical record.
- The designation of a committee or a hospital staff member and a medical staff member who are granted authority and responsibility for implementing and overseeing hospital policy and procedures on patient access to medical records and reviewing judgment thereunder.
- The steps involved in receiving and considering the patient's request for a correction of or an amendment to his medical record, including notification to the attending or responsible physician of such request and notification to the patient as to the acceptance or denial of the request.
- The establishment of a mechanism, which might consist of a committee or panel, to review denial of a patient's request to correct or amend his record.
- The establishment of special procedures to handle requests by the patient or the patient's family for access to medical records when direct access apparently could be harmful to the patient.

^{*}American Hospital Association. *A Patient's Bill of Rights*. AHA catalog no. 5009. Chicago, 1975.

- The identification of a minor's right to access to the medical record as may be permitted under general state law or state law permitting a minor to seek on his own behalf, without the knowledge or consent of his parents, treatment for certain conditions, such as venereal disease, alcohol or drug abuse, and pregnancy, and for family planning and abortion services.

However, when a claim against the hospital or its medical staff members is threatened or pending, or after suit has actually been filed, requests by patients or their attorneys or other representatives for access to the patient's medical records should be brought to the hospital attorney's attention immediately. The attorney may then advise whether, when, how, and under what circumstances such access should be granted or copies furnished to the requesters.

If state law permits a minor to obtain certain treatment without the knowledge or consent of his parents, there may be instances in which only the minor may have access to the medical record, or the minor must give consent for his parent(s) or guardian to obtain the information. Hospitals will need legal advice on any provisions related to minors in existing laws, such as in laws concerned with drug or alcohol abuse, venereal disease, certain other contagious diseases, pregnancy, family planning, and abortion.

Suggested practices for notification and access

The relationship of the hospital's medical record-keeping practices to the patient's stated interest in the medical record maintained by the hospital is that of fairness in the procedures developed to:

- Confirm to a person, upon request, whether or not a record of medical care provided is currently kept by the hospital.
- Allow a patient to find out, if the information is available, whether or not a patient-identifiable disclosure has been made to a third party and, if so, to whom it was disclosed.
- Arrange for a patient to see and/or obtain a copy of the record of medical care provided, or portions thereof, and allow the patient, if so desired, to be accompanied by a person chosen by the patient.
- Arrange for access to the medical record by a qualified medical care professional and/or other responsible person so designated by the patient when direct access by the patient is deemed medically contraindicated by the attending physician.
- Consider a patient's request for correction or amendment of the medical record and, if not granted, allow a statement of the patient's disagreement to be filed in the record of medical care provided.

The hospital should designate a specific office to which all inquiries related to a person's interest in the record of medical care provided, including those received by mail, telephone, or delivered in person, should be referred.

Hospital procedures should be developed to inform persons requesting information about a medical record or access to a record that such requests should be free from ambiguity or un-

certainty as to identification of the patient. Such requests for information should:

- Be made in writing, signed, and mailed or delivered to the designated office.
- Describe the type(s) or scope of records being sought and the manner of response desired by the inquirer.

When identification of a person or the person's designee is uncertain, the inquirer may be asked to give further or more certain identification, such as date of birth, known or approximate dates of visits or admissions to the hospital, and any known hospital identification numbers, such as medical record or account number. Persons who mail, deliver, or complete in person a written request that contains insufficient identifying or other information should be advised of the additional requirements.

Responses to all written requests pertaining to notification or access should be made promptly, if possible within 10 business days following their receipt. If a full response cannot be made within that time, an acknowledgement should be sent to indicate that a response will be forthcoming.

If there is no evidence of an existing record or if the record in question has been retired, the inquirer should be so advised.

If identification is made and the record is available, the attending or responsible physician(s) should be notified of the request.

Form letters may be prepared to:

- Confirm whether the hospital maintains, subject to record retirement policies, a medical record on the person who is the subject of the inquiry, which may indicate inpatient, outpatient, emergency service care, utilization of only departmental services, or other type of record.
- Act as a cover letter accompanying the transmission of requested information to the patient or patient's authorized representative.
- Send notices of fees, to be remitted in advance, to cover the routine costs for preparing copies.
- Notify when and where the records will be available for personal inspection.

Procedures for personal access

If a patient elects to see and/or obtain a copy of the record, the attending or responsible physician(s) should be notified and the patient should be informed that:

- The record will be available at a certain place on specified days and during given hours.
- The patient may be required to furnish adequate self-identification.
- If the patient chooses to have another person present during the review, the hospital may require the patient to sign a statement to that effect.

To ensure the integrity of a medical record during such personal

review, a designated hospital employee should be present at all times. To the extent feasible or desirable, a physician or qualified employee may be present to assist the patient in reading the entries in the record.

Requests for correction or amendment

A patient's request for correction of or amendment to the medical record should be submitted in writing and should specify the entry or entries in dispute. With the exception of requests for correction of such items as time of admission, birthdate, spelling of name, and other such admission data that can be handled by qualified employees, the attending or other responsible physician(s) should be notified of requests received for corrections or amendments. The hospital and attending physician(s) will decide whether or not the correction or amendment is to be made.

If the decision is made to correct or amend the record, the patient should be so advised. Any correction or amendment should not obliterate the material corrected.

If the request for correction or amendment is not granted, the patient should be informed that a statement of the patient's disagreement can be filed with the hospital and that the disputed entries in his medical record will be appropriately annotated to reflect this disagreement. Any further disclosure of the medical record will include this statement of disagreement and the annotations.

Model authorization for disclosure

In determining the effectiveness of an authorization for medical record disclosure, the following elements would be considered necessary under the laws of most states:

- Name or other sufficient designation of the hospital or other custodian of the medical record to which the authorization is addressed.
- Names of each person, firm, corporation, or public body to

which information or copies of records may be released by the custodian of medical records.

- Adequate designation of information to be disclosed, subject to restrictions by the patient to disclosure of a specific medical condition, injury, time period, and/or any other type of specified information.
- Signature of the patient on whom the medical record is maintained, or of a person lawfully authorized to act in the patient's behalf, and the date the authorization form was signed.
- Specified expiration date, if consistent with purpose of disclosure. For example, the patient may wish the authorization to be for a reasonable specified time period, except when an authorization is presented in connection with a life or noncancelable or guaranteed renewable health insurance policy or with payment claims for health services provided. In the absence of a contract, an authorization may be revoked by the consentor at any time.
- Agreement by the recipient not to further disclose such information, or make copies of it, unless further disclosure is expressly permitted in the original authorization or is by necessary implication inherent in the purposes of the original consent or authorization.
- Prohibition of proposed new use of information without additional written consent.

Using the desired elements of an authorization for disclosure of medical record information, authorization forms can be developed to provide a reasonable assurance that a patient may authorize disclosure only to the extent desired. A suggested form for this purpose is shown on page 8.

Other and more specialized forms may be devised for special purposes, such as release of information to facilitate payment of hospital services provided. An example of such a form is shown below.

EXAMPLE OF AUTHORIZATION FOR DISCLOSURE OF INFORMATION FOR HOSPITAL PAYMENT

Patient's name: _____

Re: Admission or hospital services commencing _____ DATE _____

The undersigned hereby authorizes _____ NAME OF HEALTH CARE PROVIDER

to release to _____ INSURANCE CARRIER(S) OR NAME OF PARTY THAT IS OR MAY BE LIABLE FOR ALL OR PART OF THE HOSPITAL CHARGES

only such diagnostic and therapeutic information (including any treatment for alcohol or drug abuse) as may be necessary to determine benefits entitlement and to process payment claims for health care services provided to the above named patient.

This authorization shall be valid only for the period of time necessary to actually process payment claims pertaining to the patient but in any case shall cease to be valid _____ years from this date.

Signature: _____ Date: _____
IF SIGNED BY PERSONAL REPRESENTATIVE, STATE RELATIONSHIP AND AUTHORITY TO DO SO

ANY DISCLOSURE OF MEDICAL RECORD INFORMATION BY THE RECIPIENT(S) IS PROHIBITED
EXCEPT WHEN IMPLICIT IN THE PURPOSES OF THIS DISCLOSURE

EXAMPLE OF AUTHORIZATION FOR DISCLOSURE OF MEDICAL RECORD INFORMATION

Subject's name: _____
LAST FIRST MIDDLE INITIAL BIRTHDATE AND AGE

Address: _____
STREET, CITY, STATE PHONE

The undersigned hereby authorizes and requests _____
HEALTH CARE OR HEALTH SERVICES PROVIDER

to provide _____
IDENTITY OF THIRD PARTY OR NAME(S) OF ANY DULY AUTHORIZED REPRESENTATIVE(S)

with access to my medical/hospital records for the purposes of review and examination and further authorizes and requests that you provide such copies thereof as may be requested.

The foregoing is subject to such limitation as indicated below:

- () 1. Confined to records regarding admission and treatment for the following medical condition or injury:

on or about _____ at the following facility: _____
DATE

- () 2. Covering records for the period from _____ to _____
DATE DATE

- () 3. Confined to the following specified information: _____
- _____

- () 4. No limitations placed on dates, history of illness, or diagnostic and therapeutic information, including any treatment for alcohol and drug abuse. (Signer to initial for authentication of this response) _____

Expiration date of this authorization, if any: _____

Signature: _____ Date: _____
IF SIGNED BY PERSONAL REPRESENTATIVE, STATE RELATIONSHIP AND AUTHORITY TO DO SO

ANY DISCLOSURE OF MEDICAL RECORD INFORMATION BY THE RECIPIENT(S) IS PROHIBITED
 EXCEPT WHEN IMPLICIT IN THE PURPOSES OF THIS DISCLOSURE

G. LETTER FROM JAMES H. SAMMONS, M.D., EXECUTIVE VICE PRESIDENT, AMERICAN MEDICAL ASSOCIATION, SUBMITTING STATEMENT ON PRIVACY OF MEDICAL RECORDS LEGISLATION



AMERICAN MEDICAL ASSOCIATION

535 NORTH DEARBORN STREET • CHICAGO, ILLINOIS 60610 • PHONE (312) 751-6000 • TWX 910-221-0300

JAMES H. SAMMONS, M.D.
Executive Vice President
(751-6200)

December 7, 1979

The Honorable Richardson Preyer
Chairman
Subcommittee on Government Information
and Individual Rights
Committee on Government Operations
United States House of Representatives
Washington, D.C. 20515

Re: HR 2979, "Federal Privacy of Medical
Records Act" and HR 3444, "Privacy
of Medical Information Act"

Dear Congressman Preyer:

The American Medical Association takes this opportunity to submit its comments on the above captioned legislation. We urge careful consideration of our views on the appropriate role of the federal government in the area of medical records privacy.

We request that this statement be made part of the formal hearing record on these bills.

Sincerely,

A handwritten signature in cursive script, reading 'James H. Sammons'.

James H. Sammons, M.D.

JHS:RDF/dap
Encl.

STATEMENT
of the
AMERICAN MEDICAL ASSOCIATION

to the
Subcommittee on Government Information
and Individual Rights
Committee on Government Operations
United States House of Representatives

Re: HR 2979, "Federal Privacy of Medical Records Act"
and HR 3444, "Privacy of Medical Information Act"

December 7, 1979

INTRODUCTION

Physicians obligate themselves to protect the confidences of their patients. This principle has been relied upon by the public and has been, in a number of states, an expression of public policy.

The obligation of physicians to keep confidential the communications of their patients is important for two reasons. First, much of the information related by patients to their physicians is highly personal. Patients have every right to expect that the intimate, personal information communicated to physicians will remain private. Second, the assurance of confidentiality encourages patients to be candid with their physicians, and candor is essential to effective diagnosis and medical management of the patient's ailments.

Even with assurances of confidentiality, some patients are reluctant to speak openly with their physicians. If the confidentiality of patient communications could no longer be protected, such reluctance could become widespread, hindering the physician's ability to provide needed medical care to his or her patients.

For most of the history of medicine, there have been few general threats to maintaining the confidentiality of the patient-physician relationship. There has been little pressure on either party to disclose identifiable, sensitive medical information.

That is no longer true. The growth of third-party payment for medical care, the increase in insurance coverage of all kinds, and expanded government involvement in medical care have combined to put great pressure on patients, physicians and institutional providers to disclose large quantities of personally identifiable medical information. Often the provider or patient has no choice but to disclose--for to withhold the information could result in a loss of the benefit or the imposition of legal penalties. Once the initial disclosure has been made, it is difficult for the individual to control subsequent disclosures and uses of the material.

These problems are compounded by the widespread use of automated data processing. The computer permits the collection and manipulation of large amounts of information that was impossible under manual records systems.

While the environment in which medical information is handled has changed radically in recent years, the sound reasons for maintaining the confidentiality of information in medical records have not. The continued development of appropriate safeguards to protect confidential medical information is very important to avoid invasion of individual rights to privacy and to preserve an essential element of good medical care.

Protecting sensitive medical information is both a public and a private responsibility. The AMA has willingly undertaken a role in carrying out that responsibility. For example, the AMA has developed model state legislation (copy attached) on medical records confidentiality. This model legislation has been widely distributed and has received acceptance in many state legislatures. The AMA has also developed guidelines for physicians on maintaining the confidentiality of computerized patient information. Adopted by the AMA House of Delegates in 1977, these guidelines have also been widely circulated (copy attached).

More recently, the House of Delegates has directed the AMA's Council on Medical Service to undertake a thorough review of the problems surrounding medical privacy. Reports and recommendations on a variety of issues are expected.

The AMA has also communicated its views on medical records privacy to the Congress and other governmental agencies. Since 1975 the AMA has submitted twenty statements to the government on this subject. These statements, too, have been well publicized.

Other groups have also been seeking to heighten awareness of privacy problems and have been taking steps to improve the protection of sensitive information. Business and industry, other associations and government at all levels are devoting increased attention to privacy issues. Nonetheless, the demands for sensitive medical information continue to expand. Thus, a continuation of these efforts by all concerned parties is essential.

Comments

Increased national attention to privacy concerns resulted from the publication in 1977 of the final report of the Privacy Protection Study Commission. The Commission made many findings and recommendations concerning medical

records confidentiality, and, shortly thereafter, several pieces of legislation were introduced to implement these recommendations. The two bills, HR 2979 and HR 3444, considered by the Subcommittee are based upon those earlier activities. HR 3444 is part of a major Presidential privacy initiative affecting many areas of personal information.

There is widespread agreement that privacy protections must be developed. Implementation of this is still subject to dispute. Major issues are (1) the appropriate roles of state and federal government, (2) access to records by the individual who is the subject of the record, and (3) permissible disclosures of identifiable information without authorization. We will address each of these issues in our comments.

Both bills before the Subcommittee would establish federal law governing the use and disclosure of identifiable medical information maintained by health care institutions.

To the extent that state laws would be inconsistent with the provisions of these bills, they would be pre-empted.

Individuals would have a right of direct access to their medical records under both bills and would be able to request correction of information in the records they believed to be erroneous.

As a general rule, disclosure of identifiable medical information could be made only with the written consent of the individual. Each bill, however, provides several exceptions to this general rule. For example, identifiable medical records could be disclosed without authorization for research, audits, law enforcement purposes, and when otherwise required by law.

Compliance by health care institutions with the provisions of these bills would be a condition of eligibility for Medicare/Medicaid reimbursement. In addition, civil and criminal penalties are provided.

Both bills also make provision for governmental access to medical records and provide procedures whereby individuals could challenge such success.

State Law or Federal Law

The AMA shares the concerns of Congress about the erosion of personal privacy and encourages continuing Congressional review and discussion of ways in which to combat these intrusions into individual privacy. However, the AMA does not believe Congress should enact comprehensive legislation, such as HR 2979 and HR 3444, that would empower the federal government to preempt state regulation of medical records confidentiality where state law is inconsistent with the federal law.

These two bills would set aside state law governing medical records maintained by health care institutions. This is an area in which the states have traditionally exercised jurisdiction and have, in recent years, been very active in defining, expanding and refining the privacy protections available to their citizens. We believe this activity should be encouraged by all who are concerned with medical records confidentiality. Adoption of this legislation, however, would have the opposite effect. We believe the states should be free to develop legislative solutions appropriate to their own circumstances and the needs of their citizens, with the federal government limiting its actions to only those areas in which states cannot act, for example, the use of medical records by federal agencies and their employees.

We do not believe that the optimum solution for problems of medical records confidentiality has been developed. Thus, we think it appropriate that experimentation in devising solutions should be encouraged. Such would be the case if each state is free to try its own ideas. From such legal experiments can come better ways of protecting personal privacy in the medical arena and in other

areas. Preemptive federal legislation would reduce the possibility for innovations that could lead to solutions. Such federal legislation should not be adopted. Furthermore, one national "solution" may not meet the needs of local communities.

Federal legislation, no matter how benign its original intent, always carries with it the risk of more federal regulations. Even a few simple lines of federal law can generate ever increasing amounts of complex federal regulation. The American people increasingly are rejecting more federal regulation and Congress is responding in many areas, properly we believe, to the wishes of the public. We believe that this message from the public should be heeded by Congress in the area of medical records privacy. We urge the Congress not to adopt this legislation.

We firmly believe that the proper role of the federal government in this area should be a limited one. Primary responsibility for the protection of medical records confidentiality should rest with the states and the private sector.

Patient Access to Medical Records

Both bills provide patients the right to examine, copy and seek correction of their medical records maintained at institutions covered by the legislation.

The American Medical Association supports the appropriate right of access to confidential health care information by the patient. There are, however, several instances, particularly in the case of psychiatric or psychological records, where the disclosure of medical information to a patient may be harmful to that individual.

In our view, an unlimited right of access to medical records or medical information could result in situations of inappropriate disclosure. For

example, certain individuals upon seeing their medical records might decide to "treat" themselves; other individuals might be unable to cope with learning about a terminal illness; individuals with psychiatric problems could seriously be harmed by learning of certain information contained in their medical records.

Both bills would permit the institution to deny direct access to the patient upon a determination that such access could be harmful to the individual. Access to the record would then be through a designated individual in lieu of the patient. While we are gratified that recognition has thus been given to some of the problems of direct patient access, we would recommend that the designated individual be a physician. Examination and discussion of medical records through a physician in all cases would provide opportunity for meaningful explanation and interpretation.

Medical records are technical documents and much of the information in them is not readily understood by patients. Patient access to medical data that results only in confusion to the patient can be harmful and would not carry out the intent to keep patients informed about their medical condition and care. If patient access to medical records is to serve the patient well, then a mechanism for such access must be devised that promotes full understanding of the information. We believe that providing access to the individual through a designated physician is a satisfactory means of assuring that the patient understands the data.

Both bills also provide that individuals may seek correction of their records in the event they believe an entry is in error. The AMA does not question the importance of reliable information in medical records, nor do we dispute the fact that erroneous information can sometimes lead to adverse consequences for an individual, such as denial of insurance or some other benefit.

However, we must question provisions that would permit correction of information in a medical record by an institution with no requirement that the institution consult with the provider who entered the information originally. We do not believe that hospital record keepers should be in the position of changing a physician's entry in a record without the agreement of the physician. An opportunity could be provided the patient to insert a statement of correction into the record.

Disclosures Without Authorization

The AMA believes that identifiable medical records should be disclosed only upon the authorization of the individual. Any exceptions to this rule should be strictly defined and allowed only upon a showing of great necessity.

For example, in HR 2979 we find the following circumstances under which an institution may release identifiable medical information without the individual's consent:

- * Disclosure to an employee of the facility maintaining the record who has a need for the record in the performance of his duties.
- * Disclosure to a medical care professional who is consulted in connection with health services provided to the individual.
- * Disclosure of admission and health status information if the individual has not objected to the disclosure.
- * Disclosure for use in a health research project determined by an institutional review board to be of sufficient importance so as to outweigh the intrusion into privacy that would result from the disclosure. Any person obtaining a record under this section must
 - (a) comply with security standards established by the Secretary;
 - (b) remove identifiers where practicable; and (c) not redisclose the record except under specified circumstances. Disclosures for

- use in another health research project which has been approved by an institutional review board are permitted.
- * Disclosure for use in an audit or evaluation. Any person obtaining a record under this section must (a) comply with security standards established by the Secretary; (b) remove identifiers where practicable; and (c) not redisclose the record except under specified circumstances.
- * Disclosures to assist in the identification of a dead person or pursuant to a showing of compelling circumstances affecting the health or safety of any person or involving imminent danger of serious property damage. A facility must keep an accounting of disclosures made under this section.
- * Disclosure where required by federal or state law.
- * Disclosure to the Secret Service or to a federal agency authorized to conduct foreign intelligence activities. Redisclosures may be made only where necessary to fulfill the purpose for which the record was obtained.
- * Disclosure of the medical record of an individual to a government authority for use in an investigation or prosecution (directed at a person other than the individual) of fraud, abuse, or waste in a government-funded program. Disclosure may also be made to a government authority to assist in the identification or location of a suspect or fugitive. A facility must keep an accounting of disclosures made under this section.
- * Disclosure pursuant to the Federal Rules of Civil or Criminal Procedure or comparable rules of other courts or agencies in connection with litigation to which the individual is a party.

* Disclosure pursuant to administrative, judicial, or grand jury summons or subpoena or pursuant to a search warrant, provided that the access procedures of the bill have been followed. Use and disclosure of information acquired by federal grand jury subpoena is limited to grand jury purposes.

HR 3444 has a similar list of exceptions and also provides that governmental agencies may seek access to personal medical records by means of a formal written request, in addition to access through warrant or subpoena.

We recognize that many of these exceptions to the general rule are justifiable and even essential. Many are incorporated in our model state bill. For example, hospital staff must have ready access to records for purposes of providing care, and important health research is often based on studies of medical records. However, we are concerned that the provisions regarding governmental access are too broad. The record of federal agencies' ability to protect the confidentiality of records they maintain is not a good one. Further, there is almost no way to control transfers of records among agencies or to ensure that subsequent uses are appropriate.

We are sympathetic to the government's desire to ferret out wrongdoing, but history teaches us that the power of government to have access to personal records and private papers must be strictly limited to preserve individual rights. The balance between individual rights and societal interests must in this case be tipped in favor of the privacy of the individual.

We believe the provision in the bill granting access merely upon an agency request is too broad. We believe that necessary government access can be satisfied through the use of subpoenas.

The AMA is especially concerned about the government access provisions in the Administration's bill, HR 3444, since they would apply to all providers, including physicians in their private offices. We believe there is already extensive access by government at all levels and that individual privacy rights are seriously jeopardized by such intrusion. We oppose any efforts to expand this governmental power.

We recognize that both bills provide challenge procedures for individuals whose medical records are sought by government authorities. It is certainly appropriate that individuals, as well as health facilities, have an opportunity to challenge government intrusions, but we question the effectiveness of these procedures to protect the individual's rights. Some people receiving the required notice of governmental intent to such access to their medical records will simply not understand their rights and the ramifications of their failure to act. Others may not be able to afford the legal representation necessary to pursue their rights properly. Further, each of the challenge procedures has provisions by which the government agency may bypass the individual's right to object. We believe these "loopholes" could make it all too easy for government officials to block any individual objections.

We suggest that the better course is to place strict limits on the ability of government agencies to obtain medical records, rather than to expand government access and cloak such expansion with challenge procedures that might not truly protect individual rights.

CONCLUSION

The American Medical Association shares with the Congress its deep concern over increasing threats to the confidentiality of medical records and the ero-

sion of privacy of patients. We are actively seeking appropriate legislative solutions to these problems, while at the same time working to educate physicians and others to be sensitive to these issues.

We do not, however, accept the need for a federal solution to this problem. We believe that the states have shown an increased willingness and ability to respond to these problems. Congress should encourage these activities, not cut them off. Accordingly, we urge the Congress not to adopt all-inclusive federal legislation, but to limit its activities to appropriate areas in which the states cannot act.

IN THE GENERAL ASSEMBLY

STATE OF _____

A Bill

To Provide For Confidentiality
Of Health Care Information

1 Be it enacted by the People of the State of _____, represented
2 in the General Assembly:
3

4 Section 1. This Act may be cited as the "Confidentiality Of
5 Health Care Information Act".
6

7 Section 2. The purpose of this Act is to establish safeguards
8 for maintaining the integrity of confidential health care information.
9

10 Section 3. For purposes of this Act --
11

12 (a) the term "health care provider" means any person,
13 corporation, facility or institution licensed by this state to
14 provide or otherwise lawfully providing health care services, including
15 but not limited to a physician, hospital or other health care facility,
16 dentist, nurse, optometrist, podiatrist, physical therapist or psycholo-
17 gist, and an officer, employee or agent of such provider acting in
18 the course and scope of his employment or agency related to or sup-
19 portive of health care services;
20

21 (b) the term "health care services" means acts of
22 diagnosis, treatment, medical evaluation or advice or such other acts
23 as may be permissible under the health care licensing statutes of
24 this state;
25

26 (c) the term "confidential health care information" means
27 information relating to a person's health care history, diagnosis,
28 condition, treatment, or evaluation;
29

30 (d) the term "medical peer review committee" means a com-
31 mittee of a state or local professional medical society or of a
32 medical staff of a licensed hospital, nursing home or other health care
33 facility provided the medical staff operates pursuant to written
34 bylaws that have been approved by the governing board of the hospital,
35 nursing home, or other health care facility, or other organization of
36 physicians formed pursuant to state or federal law and authorized to
37 evaluate medical and health care services;
38

39 (e) the term "third party" means a person or entity
40 other than the person to whom the confidential health care informa-
41 tion relates and other than a health care provider.

Section 4. (a) Except as provided in subsection (b) or as otherwise specifically provided by law, a person's confidential health care information shall not be released or transferred without the written consent, on a consent form meeting the requirements of section 4 (d) of this Act, of such individual or his authorized representative. A copy of any notice used pursuant to section 4 (d), and of any signed consent shall be provided to the person signing a consent form.

(b) No consent for release or transfer of confidential health care information is required in the following situations: (1) to a physician, dentist, or other medical personnel for diagnosis or treatment of such individual in a medical or dental emergency, or (2) to medical peer review committees, or (3) to a State Insurance Department or other state agency for the purpose of reviewing an insurance claim or complaint made to such Department or other agency by an insured or his authorized representative or by a beneficiary or his authorized representative of a deceased insured, or (4) to qualified personnel for the purpose of conducting scientific research, management audits, financial audits, program evaluations, or similar studies, but such personnel shall not identify, directly or indirectly, any individual patient in any report of such research, audit, or evaluation, or otherwise disclose patient identities in any manner (the term "qualified personnel" means persons whose training and experience are appropriate to the nature and level of the work in which they are engaged and who, when working as part of an organization, are performing such work with published and adequate administrative safeguards against unauthorized disclosures), (5) by a health care provider, as reasonably necessary in the provision of health care services to a person, or in the administration of the office or practice or operation of a health care provider (as used herein, "administration" shall include, but not be limited to, purposes of: accreditation, reimbursement, liability risk management or appraisal, and defense or prosecution of legal actions), or (6) by an employer as reasonably necessary in the administration of a group insurance or workmen's compensation plan, or (7) upon the filing of a claim for insurance benefits, between third party insurers to determine their relative rights and obligations concerning the individual's entitlement or the amount or kind of insurance benefits, when the policy of insurance obtained by the individual provides for obligations by more than one insurer with respect to a claim for benefits.

The release or transfer of confidential medical information under any of the above exceptions shall not be the basis for any legal liability, civil or criminal, nor considered a violation of this Act.

(c) Third parties receiving and retaining an individual's confidential health care information must establish at least the following security procedures: (1) limit authorized access to personally identifiable confidential health care information to persons having a "need to know" such information; additional employees or agents may have access to such information which does not contain information from which an individual can be identified; (2) identify an individual

or individuals who have responsibility for maintaining security procedures for confidential health care information; (3) provide a written statement to each employee or agent as to the necessity of maintaining the security of confidential health care information, and of the penalties provided for in this Act for the unauthorized release, use, or disclosures of such information; receipt of such statement shall be acknowledged by such employee or agent signing and returning same to his employer or principal and the employer or principal shall furnish his employee or agent with a copy of the signed statement, and shall retain the original thereof; (4) take no disciplinary or punitive action against any employee or agent who brings evidence of violation of this Act to the attention of any person or entity.

(d) Consent forms for the release or transfer of confidential health care information shall contain, or in the course of an application or claim for insurance be accompanied by a notice containing, at least the following:

(1) the need for and proposed use of such information;

(2) a statement that all information is to be released or indicating the extent of the information to be released, and

(3) a statement that such information will not be given, sold, transferred, or in any way relayed to any other person or entity not specified in the consent form or notice without first obtaining the individual's additional written consent on a form stating the need for the proposed new use of such information or the need for its transfer to another person or entity, and,

(4) a statement that such consent applies only to the release or transfer of confidential health care information existing prior to the date such consent is signed, except that when such consent is given in the course of an application or claim for insurance it shall also apply to medical information existing at any time during the period of contestability provided for in the policy and during periods of ongoing proofs of loss during a claim.

Section 5. (a) Upon occurrence of an action or decision of any third party, which adversely affects a person, and which is based in whole or in part upon his confidential health care information, including, but not limited to, the following actions or decisions:

(1) denial of an application for an insurance policy; (2) issuance of an insurance policy with other than standard and uniform restrictions;

(3) rejection in whole or in part of any claim for insurance benefits;

(4) denial of an employment application or termination of employment when such denial or termination is for health reasons; and upon the written request of such person or his authorized representative (or, if such person is deceased, then his heir or beneficiary or their authorized representative or his estate), a third party shall transfer all of such person's confidential health care information in its possession to a physician designated in such written request.

Prior to making such transfer, a third party may require payment of its actual cost of retrieval, duplication and forwarding of such information.

(b) A physician receiving confidential health care information pursuant to (a) above, may review, interpret and disclose any or all of such information to the person at whose request such information was transferred, as said physician deems in his professional judgment to be in the best interests of the person to whom such information relates.

(c) After reviewing his confidential health care information pursuant to this Section, a person or his authorized representative may request the third party to amend or expunge any part he believes is in error, or request the addition of any recent relevant information.

Upon receiving such a request, the third party shall notify the health care provider who initially forwarded such information to the third party, and when such health care provider concurs with such request, the third party shall return such information to that health care provider for modification. Prior to making such return, a third party may require payment of its actual cost of notice, duplication, and return of such information. Except upon court order, the third party shall not itself modify such information. A person after requesting and reviewing his confidential health care information shall have the right, in any case, to place into the file a statement of reasonable length of his view as to the correctness or relevance of existing information or as to the addition of new information. Such statement or copies thereof shall at all times accompany that part of the information in contention.

Section 6. (a) (1) Except as provided in subparagraph (2) hereof, confidential health care information shall not be subject to compulsory legal process in any type of proceeding, including, but not limited to, any civil or criminal case or legislative or administrative proceedings or in any pre-trial or other preliminary proceedings, and a person or his authorized representative has a privilege to refuse to disclose, and to prevent a witness from disclosing, his confidential health care information in any such proceedings.

(2) The exemption from compulsory legal process and the privilege provided in subparagraph (1) above shall not apply when:

(A) an individual introduces his physical or mental condition, including, but not limited to, any allegation of mental anguish, mental suffering or similar condition as an element of his claim or defense, provided that a claim for damages or other relief for "pain and suffering" based solely on one's physical condition does not constitute the introduction of one's mental condition into issue and the exemption and privilege shall apply in such situation as to those portions of one's confidential health care information relating to mental condition.

(B) the individual's physical or mental condition is relevant regarding the execution or witnessing of a will or other document;

(C) the physical or mental condition of a deceased individual is introduced by any party claiming or defending through or as a beneficiary of such individual;

(D) in a civil or criminal commitment proceeding, a physician, in the course of diagnosis, treatment, or medical evaluation of an individual, determines that an individual is in need of care and treatment in a hospital or any other health care facility which is deemed by the individual's physician to be appropriate for mental illness;

(E) a judge finds that an individual, after having been informed that the communications would not be privileged, has made communications to a psychiatrist in the course of a psychiatric examination ordered by the court, provided that such communications shall be admissible only on issues involving the individual's mental condition;

(F) in any court proceeding, including an ex parte hearing, it is demonstrated on a prima facie basis to the court that the individual's physical or mental condition is of an imminent and serious danger to the physical or mental health of another person, or to the security of the United States, or

(G) in any action by an individual pursuant to Section 9 of this Act, or in any policy action brought by an individual against his insurance carrier, or by the carrier against an insured, or in any other action by an individual wherein it is demonstrated to the court that such confidential health care information is relevant and material then such court may issue an order compelling production of such information.

(b) The exceptions contained in items (A) through (G) of subparagraph (2) above are not intended to preclude the exemption or privilege described in subparagraph (1) above in any pretrial or trial proceedings under the Divorce Act of this State unless the individual or witness on his behalf first testifies as to such confidential health care information.

Section 7. (a) Notwithstanding other provisions of this Act, health care providers may make confidential health care information available to medical peer review committees without authorization.

(b) Confidential health care information before a medical peer review committee shall remain strictly confidential, and any person found guilty of the unlawful disclosure of such information shall be subject to the penalties provided in this Act.

1 (c) Except as otherwise provided in this Section, the proceed-
 2 ings and records of medical peer review committees shall not be subject
 3 to discovery or introduction into evidence. No person who was in
 4 attendance at a meeting of such committee shall be permitted, or re-
 5 quired to testify as to any matters presented during the proceedings
 6 of such committee or as to any findings, recommendations, evaluations,
 7 opinions or other actions of such committee or any members thereof.

8
 9 Confidential health care information otherwise discoverable or
 10 admissible from original sources is not to be construed as immune
 11 from discovery or use in any proceeding merely because they were
 12 presented during proceedings before such committee, nor is a mem-
 13 ber of such committee or other person appearing before it to be
 14 prevented from testifying as to matters within his knowledge and in
 15 accordance with the other provisions of this Act, but the said witness
 16 cannot be questioned about his testimony or other proceedings before
 17 such committee or about opinions formed by him as a result of said
 18 committee hearings.

19
 20 (d) The provisions of sub-section (c) above limiting discovery
 21 or testimony do not apply in any legal action brought by a medical
 22 peer review committee to restrict or revoke a physician's hospital
 23 staff privileges, or his license to practice medicine, or to cases
 24 where a member of the medical peer review committee or the legal
 25 entity which formed such a committee or within which such committee
 26 operates is sued for actions taken by such committee, provided that in
 27 any such legal action personally identifiable portions of a person's
 28 confidential health care information shall not be used without
 29 written authorization of such person or his authorized representative
 30 or upon court order.

31
 32 (e) Nothing in this Act shall limit the authority, which may
 33 otherwise be provided by law, of a physician licensing or disciplinary
 34 board of this State to require a medical peer review committee to
 35 report to it any disciplinary actions or recommendations of such
 36 committee, or to transfer to it records of such committee's proceedings
 37 or actions, including confidential medical information, or restrict
 38 or revoke a physician's license to practice medicine, provided that
 39 in any such legal action personally identifiable portions of a
 40 person's confidential health care information shall not be used with-
 41 out written authorization of such person or his authorized repre-
 42 sentative or upon court order.

43
 44 (f) No member of a medical peer review committee nor the legal
 45 entity which formed or within which such committee operates nor any
 46 person providing information to such committee shall be criminally
 47 or civilly liable for the performance of any duty, function, or acti-
 48 vity of such committee or based upon providing information to such
 49 committee; provided such action is without malice and is based upon
 50 a reasonable belief that such action is warranted.

51
 52 Section 8. (a) Civil Penalties - Anyone who violates provisions
 53 of this Act, may be held liable for special and general damages, and

1 punitive damages may be granted for malicious violation of this Act.

2
3 (b) Criminal Penalties - Anyone who intentionally and knowingly
4 violates provisions of this Act shall, upon conviction, be fined not more
5 than \$5,000, or imprisoned for not more than one year, or both.

6
7 (c) The civil and criminal penalties above shall also be applicable
8 to anyone who obtains an individual's confidential health care information
9 through the commission of a crime.

10
11 Section 9. A person or his authorized representative shall have the
12 right, when there is an unreasonable refusal to change the records as
13 provided in Section 5, to seek through court action the amendment or ex-
14 punctionment of any part of his confidential health care information in a
15 third party's possession which he believes is erroneous.

16
17 Section 10. Attorney's fees and reasonable costs may be awarded,
18 at the discretion of the court, to the successful party in any action
19 under this Act.

20
21 Section 11. Any agreement purporting to waive the provisions of
22 this Act is hereby declared to be against public policy and void.

23
24 Section 12. If any provision of this Act is held by a court to be
25 invalid, such invalidity shall not affect the remaining provisions of
26 this Act, and to this end the provisions of this Act are hereby declared
27 severable.

28
29 Section 13. This Act shall become effective _____ (one year)
30 from the date of being signed into law.

(Joint Report)

JOINT REPORT OF JUDICIAL COUNCIL AND COUNCIL ON MEDICAL SERVICE

The following report was presented by Burns A. Dobbins, Jr., M. D., Chairman of the Judicial Council, and Donald N. Sweeny, Jr., M. D., Chairman of the Council on Medical Service:

CONFIDENTIALITY OF COMPUTERIZED PATIENT INFORMATION (RESOLUTION 38, A-77) (Reference Committee A, page 234)

HOUSE ACTION: ADOPTED

At the 1977 Annual Convention, the House of Delegates adopted Resolution 38 (A-77), as amended, asking that guidelines be established to (1) define procedures for the management of a computerized patient data base, (2) define procedures to control access to clinical data and limit access to the computerized data base, and (3) establish accrediting guidelines for computer service bureaus to reassure patients and physicians that their information will not be misused.

Background

The issues of access to confidential medical and other personal information and the use of such information once computer technology has permitted the accumulation, storage, and analysis of an unlimited quantity of it have been under discussion in both the public and private sectors for more than a decade. Legislation at both the state and federal levels has focused on policies governing the release of various kinds of information, with particular emphasis given to the patient's right to have access to confidential medical information, to have an opportunity to be informed of the use to be made of it, and to have access to it for making corrections. The House of Delegates has, on a number of past occasions, adopted reports dealing with issues related to confidentiality of medical information, including guidelines on PSRO data policy developed by the Council on Medical Service, and model state legislation on confidentiality of medical information developed by the Council on Legislation.

The federal Fair Credit Reporting Act, the National Health Planning and Resources Development Act, the Professional Standards Review Organization amendments to the Social Security Act, and the federal Privacy Act are examples of the Congressional interest in the right of individuals to have certain types of information protected and to be assured access to such information in the custody of specified agencies and entities. At the federal level, for instance, the Fair Credit Reporting Act sets requirements concerning the accumulation, verification, and release of medical record information obtained by a proper credit reporting agency. Information relating to medical practice and care also may be accumulated by the Bureau of Census, HEW, the Secretary of Commerce, Health Systems Agencies, and other governmental agencies.

Two major research studies undertaken for the federal government on these issues were completed in 1976 and 1977. The publications based on these studies are: "Computer, Health Records and Citizen Rights" by Alan F. Westin, Ph.D., principal investigator, and "Personal Privacy in an Information Society—The Report of the Privacy Protection Study Commission,"

Daniel F. Linowes, Chairman. The Report of the Privacy Protection Study Commission recommended, among other things, the creation of Medicare and Medicaid regulations and State legislation to assure patient access to medical records and related medical record information, to allow correction of medical records, and to assure both the protection of confidentiality of information and the disclosure of information pursuant to patient authorization.

At the state level, at least eleven legislatures have enacted statutes in the past four years to allow patients greater access to the information contained in medical records that concern patients' care or treatment. Other states have rules and regulations on this subject. Although the traditional professional and legal view has been that a physician is entitled to possession or ownership of the medical notes he makes in his private practice, a patient or his legal representative may also have certain legal rights to the information in such notes. The patient does have a right to information from the records, at least to the extent that the information is necessary to protect his health interests or legal rights. In those states that have specific statutory language or rules and regulations governing access to medical records, compliance with these requirements is mandated.

A physician also has a professional responsibility to keep information secret about a patient that is obtained in the course of the physician-patient relationship. Section 9 of the Principles of Medical Ethics states: "A physician may not reveal confidences entrusted to him in the course of medical attendance, or the deficiencies he may observe in the character of patients, unless he is required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or of the community."

The confidentiality of physician-patient communications is desirable to assure free and open disclosure by the patient to the physician of all information needed to establish a proper diagnosis and attain the most desirable clinical outcome possible. Protecting the confidentiality of the personal and medical information in such medical records is also necessary to prevent humiliation, embarrassment, or discomfort of patients.

At the same time, patients may have legitimate desires to have medical information concerning their care and treatment forwarded to others. The increasing incidence of personal injury litigation and the expanding use of life, accident and health insurance, for example, are major factors which have operated to multiply the number of persons who have a legitimate interest in the information. It may, for instance, be desirable for a patient to have certain information transmitted directly to third parties concerned with the payment of the patient's bill, to a workmen's compensation commission, to the patient's attorney, to a succeeding attending physician, to a physician with a professional or academic interest in the type of case, to a law enforcement agency, to military authorities, to a prospective employer, or to others. Patient authorization for release of information to a third party payor that has legal liability for the payment of any part of the charges for the medical care and treatment provided may be the most commonly encountered instance in which the patient's expectation of authorized release should be honored.

In summary, both the protection of confidentiality and the appropriate release of information in records is the rightful expectation of the patient. A physician should respect the patient's expectations of confidentiality concerning medical records that involve the patient's care and treatment, but the physician should also respect the patient's authorization to provide information from the medical records to those whom the patient authorizes to inspect all or a part of it for legitimate purposes.

Discussion

Resolution 38 (A-77), as amended, requested the development of guidelines applicable to information from a physician's office records that is made part of a computerized data system. The transfer of such information would, generally, be expected to occur when a computer service bureau contracts with a physician to store data on patient billing or on the care and treatment provided the physician's patients. Although computerized data concerning patient care and treatment could involve many other data systems, such as that used by peer review bodies, Health Systems Agencies, third party insurance carriers and intermediaries, and PSROs, the guidelines presented in this report will be limited primarily to the situation of computerized office records, in keeping with the major thrust of amended Resolution 38.

There are three primary issues that need to be addressed to assure the maintenance of confidentiality of information from medical records stored in computerized data banks by computer service bureaus. These three related issues are privacy, confidentiality, and security. The issue of privacy concerns the obligation to withhold personal information from revelation. There is certain information, such as may be kept in a medical record, that a patient may not want disclosed solely for personal reasons. The issue of confidentiality concerns an agreement between individuals to limit the extent of revelation of such personal information. The patient's expectations of confidentiality arise from the obligation to protect the patient's privacy and from the clinical desirability of such an agreement to allow a free flow of information between the physician and the patient. As has been noted above, there may be limitations on a patient's expectations of confidentiality. The third issue, security, concerns a responsibility to protect personal information from revelation so as to preserve confidentiality.

Computer technology permits the accumulation, storage, and analysis of an unlimited quantum of medical information. The fact that the data bases are increasing substantially is evidence of increased pressure to obtain medical data for clinical, administrative, and archive purposes. Although the concepts of privacy, confidentiality, and security apply to all medical data regardless of collection or storage method, the ability of the computer to store vast amounts of medical data has resulted in public and private scrutiny of this technology to guard against its accidental or intentional misuse. Such misuse may occur because of inadequate security policies or improper training of personnel. The harm that results from the misuse of such data may be felt by the patient, whether the misuse is accidental or intentional.

Because of the technological growth of medical data acquisition mechanisms, the fundamental need to protect the confidentiality of information from medical records has been intensified. The fact that such data may reside in a computerized data bank does not alter this need.

The possibility of access to information is greater with a computerized data system than with information stored in the traditional written form in a physician's office. Accordingly, the guidelines noted below are offered to assist computer service organizations and physicians in maintaining the confidentiality of information in medical records when that information is stored in computerized data bases. Commentary on specific guidelines is also included to show the need for certain particular rules and standards for computerized medical information.

The Council on Medical Service and the Judicial Council, therefore, recommend that the House of Delegates adopt the following guidelines addressing the issues spoken to by amended Resolution 38 (A-77).

GUIDELINES ON PROCEDURES FOR THE MANAGEMENT OF A COMPUTERIZED DATA BASE

Introduction

Management of computerized data bases involves the planning, organization and control of activities or programs directed towards satisfying an established set of operational objectives. With respect to the management of a computerized data base holding medical information, guidelines have been requested by the House of Delegates in order to assure the maintenance of confidential treatment and management of essentially private patient data. The management guidelines noted below reflect concepts desirable from a medical viewpoint related to computer technology capable of storing confidential medical information. It should be recognized that specific procedures adapted from application of these concepts may vary depending upon the nature of the organization processing the data as well as the appropriate and authorized use of the stored data.

1. PREFACE: Medical information maintained on a patient's behalf is often used as the basis for important clinical or administrative decisions affecting the patient. Accordingly, only specifically authorized individuals should be permitted to submit additions, changes, or deletions to the computerized data base holding medical information.

GUIDELINE: Procedures should be developed to insure that confidential medical information entered into the computerized data base is verified as to authenticity of source.

2. PREFACE: Once a physician has released a patient's confidential medical information on the patient's authorization, subsequent use of that information is out of the physician's effective control. The physician should be advised about the destination of medical information released from his control.

GUIDELINE: Procedures should be developed to advise the patient and physician about the existence of computerized data bases in which the patient's medical information is stored. Such information should be communicated to the physician and patient prior to the physician's release of the medical information.

3. PREFACE: Due to the ease with which information can be produced from a computer, it is important to identify and trace all reports on which is printed identifiable patient data.

GUIDELINE: Procedures should be developed for notifying both the physician and patient of the distribution of all reports reflecting identifiable patient data prior to distribution of the reports by the computer facility.

4. PREFACE: Too often an unwarranted assumption may be made that the data coming from a computerized data base is correct. Management of the computerized medical data must, therefore, include mechanisms to maintain the patient data in an as accurate a state as possible.

GUIDELINE: Procedures should be developed for adding to or changing data on the computerized data base. The procedures should indicate individuals authorized to make changes, time periods in which changes take place and those individuals who will be informed about changes in the data from the medical records.

5. PREFACE: Due to the large storage capacity of computers, there exists the possibility that once data is entered into the data base it will not be subsequently removed even if the data has no contemporary or historical value.

GUIDELINE: Procedures for purging the computerized data base of archaic or inaccurate data should be established and the patient and physician should be notified before and after the data has been purged.

6. PREFACE: Once a computerized data base is physically linked to the computer, it becomes relatively easy to gain access to that data base. Care should, therefore, be taken not to connect the data files to the computer except as necessary to perform legitimately defined processing.

GUIDELINE: The computerized medical data base should be on-line to the computer only when authorized computer programs requiring the medical data are being used.

7. PREFACE: To prevent misuse of data, it is advisable to permit only authorized computer service personnel to enter or work in the physical facility in which processing is done and the computer files are stored.

GUIDELINE: Stringent security procedures for entry into the immediate environment in which the computerized medical data base is stored and/or processed should be developed and strictly enforced.

8. PREFACE: Procedures for the maintenance of the confidentiality of medical data should be communicated to employees involved in activities related to the computerized medical data base. It is equally important that employees be advised of administrative remedies for breaches of confidentiality which may place in peril the confidential patient data.

GUIDELINE: (a) Specific guidelines concerning behavior of employees handling or otherwise having access to confidential medical information should be developed and be made generally available to affected employees.

(b) All terminated or former employees in the data processing environment should have no access to data from the medical records concerning patients.

(c) Employees working in the data processing environment in which data from medical records concerning patients are processed and who are involuntarily terminated should immediately upon termination be removed from the computerized medical data environment.

II. GUIDELINES ON PROCEDURES WHICH CONTROL ACCESS TO CLINICAL DATA AND LIMIT ACCESS TO THE COMPUTERIZED DATA BASE

Introduction

In general, the recorded instances of theft or misuse of computerized data are few compared to those instances in which information maintained in conventional, non-computerized data repositories are misused or stolen. The recorded instances of computerized data misuse, however, suggest that when such an occurrence takes place, it involves exceptionally large segments of information. Such misuse may be more extensive than realized, since it may not be reported or

may remain cloaked due to the technical abilities of those involved in the misuse of data. The recounting of such occurrences of misuse suggests that the problem is generally not one of access by unauthorized individuals, but stems from the misuse of computerized data (either consciously or inadvertently) by those who have authorized access to the data. Hence, with respect to computerized data bases holding medical data, emphasis should be placed upon controlling the mechanism for authorized access to medical data as well as defining the limits of such permissible authorized access.

1. PREFACE: Once an individual or organization has gained physical access to the computer data base, either via remote computer terminal or other means, it becomes extremely difficult, if not virtually impossible, to prevent access to those portions of the data base which have not been authorized for release.

GUIDELINE: Individuals and organizations external to the clinical facility should not be provided on-line access to a computerized data base containing identifiable data from medical records concerning patients.

2. PREFACE: The patient and physician should be cognizant of those individuals or organizations that will have access to the computerized files of medical information concerning the patient. Such safeguards are important in a computer environment because of the relative ease with which large segments of data can be transferred from one computer to another.

GUIDELINE: Procedures should be developed to obtain the approval by the physician and patient prior to the release of patient-identified clinical and administrative data to individuals or organizations external to the medical care environment.

3. PREFACE: Due to the complexity of the health care environment, secondary and tertiary users of medical data are becoming more prevalent. Increasingly prolific dispersion of computerized medical data endangers the confidentiality of these data.

GUIDELINE: As a corollary to Guideline Number 2, procedures should be developed to provide the patient with advance notification of any agency or individual with access to patient-identifiable medical data.

4. PREFACE: The probability of leakage of confidential medical data increases the longer the data is external to the controlled access data base environment. In addition, the probability of the data being used for unauthorized purposes increases.

GUIDELINE: Procedures should be developed to limit the dispersion of confidential medical data only to those individuals or agencies with a bona fide use for the data. Release of confidential medical information from the data base should be confined to the specific purpose for which the information is requested and limited to the specific time frame requested.

5. PREFACE: The organization should designate an individual who is directly accountable for the manner in which and the success with which defined confidentiality procedures are implemented. This requirement may help to minimize errors of omission or commission with respect to observance of confidentiality procedures.

GUIDELINE: The organization should designate a "security officer" with the duty to implement and monitor confidentiality procedures and policies.

6. PREFACE: Once confidential medical information is released to other organizations, effective control over subsequent use of the data is greatly diminished. Accordingly, organizations receiving such medical data should be sensitized to the data's confidential nature and limitations on its use.

GUIDELINE: Data release limitations should be specifically stated for organizations or individuals receiving confidential medical data, such as PSROs, peer review bodies, Health Systems Agencies, and third party insurance intermediaries. All such organizations or individuals should be advised that authorized release of data to them does not authorize their further release of the data to additional individuals or organizations.

7. PREFACE: Since individuals and organizations authorized to have access to computer data bases will have differing needs for access to the computer for legitimate purposes, the level of access to the data needed by the individual or organizations involved should be specified.

GUIDELINE: All individuals and organizations with some form of access to computerized data bank, and level of access permitted, should be specifically identified.

III. ACCREDITING GUIDELINES FOR COMPUTER SERVICE BUREAUS

Introduction

An increasing number of computer service bureaus are expanding their services to include provision of data processing support for physicians who wish to automate their patient billing and for production of insurance reports for third party intermediaries. In the performance of this activity, the computer service bureau maintains computerized medical data bases which include medical information (e.g., diagnosis, service provided) used to produce the items noted above. As much of the data maintained by a computer service bureau is sensitive, it is important that these organizations establish explicit confidentiality procedures to protect against intentional or inadvertent release of confidential medical information to individuals or organizations not authorized to receive it.

The guidelines noted below are not intended to serve in the same manner as standards established by a voluntary accreditation agency. The guidelines are intended to suggest procedures to preserve the confidentiality of medical data the computer service bureau maintains when providing service for physicians and the patients they serve.

1. PREFACE: Only authorized computer service bureau personnel are to be permitted within the area in which computerized medical data base information is processed or stored so as to prevent unauthorized disclosures.

GUIDELINE: The computer service bureau should specifically identify a physical security procedure to prevent access to the computer facility by unauthorized personnel.

2. PREFACE: In the event that unauthorized disclosure of medical data does take place, it is important to be able to identify the source of the disclosure so as to prevent repeated occurrences.

GUIDELINE: Personnel audit procedures should be developed to establish a record in the event of unauthorized disclosure of medical data. A roster of past and present service bureau personnel with specified levels of access to the medical data base should be maintained.

3. PREFACE: A computer-generated report for one client may reflect a segment of data maintained on behalf of a different client. This generally arises either because all client data is maintained on a central data base or because client reports are the product of one continuous computer run and a segment of one client's report is inadvertently combined with that of another client. In the case of medical data, such an error would represent a serious breach of confidentiality.

GUIDELINE: Procedures should be developed to prevent the commingling of a physician's computerized records with those of other service bureau clients. In addition, procedures should be developed to protect against inadvertent mixing of client reports or segments thereof.

4. PREFACE: Inadvertent release of patient-identified medical data to unauthorized recipients should be avoided at all costs. Hence specific individuals or organizations to whom information is to be sent should be qualified as authorized data recipients prior to forwarding the information.

GUIDELINE: Information on a physician's computerized medical data base should under no circumstances be released without the express permission of the physician and the patient. This stipulation should appear in any agreement between the computer service bureau and the physician which addresses work to be performed for the physician.

5. PREFACE: In addition to management personnel, it is important that other computer service bureau employees be made aware of the sensitive nature of medical data and the proper conduct for handling such data.

GUIDELINE: Procedures should be developed to advise computer service bureau employees of the confidential nature of the medical data processed. These procedures should explicitly address employee responsibilities. Specific administrative sanctions should exist to prevent employee breaches of confidentiality and security procedures.

6. PREFACE: The computer service bureau agreements with some physician clients may be terminated. Upon such termination of services, the disposition of the computerized medical data maintained for the physician is important. Under no circumstances should the medical information be retained by the computer service bureau after services for the physician have ceased.

GUIDELINE: Upon termination of computer service bureau services for a physician, those computer files maintained for the physician should be physically turned over to the physician or destroyed (erased). In the event of file erasure, the computer service bureau should verify in writing to the physician that the erasure has taken place.

7. PREFACE: As the preservation of confidentiality is of significant importance to both the patient and physician, the computer service bureau should, upon request, notify the physician and the patient about the procedures taken to keep confidential the medical data on patients.

GUIDELINE: The computer service bureau is strongly encouraged to make available to physicians and patients a brochure or other written document, which, in specific terms, outlines the procedures the computer service bureau uses to protect the confidentiality of patient-identifiable medical data processed by the facility.

(Committee A)

REFERENCE COMMITTEE A

Jokichi Takamine, California, Chairman
 Henry A. Crawford, Ohio
 William Carl Ebeling, Maryland

James F. McDonough, Massachusetts
 Russel H. Patterson, Section on
 Neurological Surgery

- (1) JOINT REPORT OF COUNCIL ON MEDICAL SERVICE
 AND JUDICIAL COUNCIL — CONFIDENTIALITY
 OF COMPUTERIZED PATIENT INFORMATION
 (RESOLUTION 83, A-77)

The Council on Medical Service and the Judicial Council Joint Report concerning confidentiality of computerized patient information addresses Resolution 38 (A-77), as amended. In response to Resolution 38, the Joint Report defines guidelines to assist computer service organizations and physicians in maintaining the confidentiality of medical record information stored in computerized data bases.

RECOMMENDATION:

Mr. Speaker, your Reference Committee commends the Council on Medical Service and the Judicial Council for their efforts in developing this definitive document and recommends that the Joint Report of the Council on Medical Service and the Judicial Council on "Confidentiality of Computerized Patient Information" be adopted. (see page 90)

- (2) RESOLUTION 6 — NATIONAL COMMISSION ON
 CONFIDENTIALITY OF HEALTH RECORDS

Resolution 6 asks that the American Medical Association join the National Commission on Confidentiality of Health Records as an active member.

RECOMMENDATION:

Mr. Speaker, your Reference Committee recommends that Resolution 6 be referred to the Board of Trustees for study and report at the 1978 Annual Convention. (see page 202)

- (3) REPORT P OF BOARD OF TRUSTEES
 MEDICARE REIMBURSEMENT POLICY
 (SUBSTITUTE RESOLUTION 80, A-77)

Board of Trustees Report P is an informational report describing draft legislation developed by the Council on Legislation in response to Substitute Resolution 80 (A-77). The draft

(Not Final Action of the House)

APPENDIX 2.—LETTERS COMMENTING ON PRIVACY OF MEDICAL RECORDS LEGISLATION

A. LETTER FROM WILLIAM FOLEY, DIRECTOR, ADMINISTRATIVE OFFICE OF THE UNITED STATES COURTS

ADMINISTRATIVE OFFICE OF THE UNITED STATES COURTS

WASHINGTON, D.C. 20544

WILLIAM E FOLEY
DIRECTOR

JOSEPH F SPANIOL, JR
DEPUTY DIRECTOR

APR 26 1979

April 23, 1979

Honorable Richardson Preyer
House of Representatives
2344 Rayburn House Office Building
Washington, D.C. 20515

Dear Congressman Preyer:

I am writing in reference to two bills which you recently introduced to protect the privacy of medical records. Both H.R. 2979 and H.R. 3444 include provisions that would allow an individual who wishes to challenge a government summons or subpoena for his medical records to file a motion to quash such summons or subpoena in a United States district court. H.R. 3444 provides additionally for the filing of an application to enjoin a government authority from obtaining medical information about an individual pursuant to a formal written request.

Section 209(a) of H.R. 3444 contains language that would eliminate filing fees in connection with challenges to the government's obtaining access to an individual's medical records. No reference of any kind is made to filing fees, however, in the corresponding section (§ 142(a)) on challenge procedures in H.R. 2979. Because of a problem that we recently had in connection with a similar procedure in the Right to Financial Privacy Act of 1978, Pub. L. No. 95-630, 92 Stat. 3697 (Nov. 10, 1978), we would favor the bill which contains an explicit waiver of the filing fee requirement.

The problem arose because, in spite of an expressed congressional intent that no fee be charged against an individual who filed a motion to quash or an application to enjoin pursuant to the customer challenge provisions of the Financial Privacy Act, we have had to advise that a fee was nonetheless required by 28 U.S.C. § 1914 inasmuch as the filing would constitute the commencement of a proceeding in district court. Since no waiver of the filing fee was written into the Act itself, there was no way for us to circumvent the requirement of section 1914. Accordingly, if it is the intent of Congress that a fee not be charged in connection with filings to challenge the release of medical records to government authorities, we hope that a similar misunderstanding can be averted by adoption of the provision found in section 209(a) of H.R. 3444, or of similar language that makes explicit the congressional intent in this matter.

The method by which a government authority is permitted to seek an individual's medical records is, of course, a matter of congressional policy. I might note, however, that there may be advantages to requiring a government authority which is seeking access to an individual's medical records to proceed by way of applying for a judicial writ. This suggestion is based upon considerations set forth in Reisman v. Caplin, 375 U.S. 440 (1965), which raise some question as to the authority of a court to review the validity of an administrative subpoena on the basis of an original challenge by the person being subpoenaed. It appears that this problem might be avoided by eliminating the use of an administrative subpoena or summons as a method of obtaining medical information about an individual. Ultimately, however, this is a question for the Congress to decide.

An additional concern we have is with the effect your bills would have on the ability of certain officers and employees of the federal judiciary to obtain access to an individual's medical records. It is essential, for example, that United States probation officers have access to medical information about persons under their supervision in order to effectively carry out their presentence responsibilities and maintain supervision over such persons while they are on probation or parole or during the course of a drug aftercare program. Similarly, United States pretrial service officers must have access to the medical records of persons under their supervision pursuant to the pretrial release provisions of §§3153 and 3154 of title 18, United States Code. For this reason I would like to request that language be included in both bills that would specifically provide for the release of medical records to United States probation and pretrial service officers.

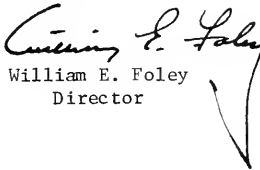
We are also concerned that the ability of a federal public defender to obtain medical records pursuant to a judicial subpoena for discovery purposes in a criminal proceeding not be impeded by your legislation. Ordinarily a federal public defender who wishes to obtain the medical records of an individual would have such records subpoenaed pursuant to Rule 17 of the Federal Rules of Criminal Procedure. Section 105(b)(20) of H.R. 3444 authorizes the disclosure of medical information to a person other than a government authority pursuant to compulsory legal process. We presume that this provision would allow current discovery practices to continue unhampered. However, H.R. 2979, by virtue of section 130(a), would only permit the disclosure of medical records if the disclosure is made pursuant to the Federal Rules of Civil or Criminal Procedure in connection with litigation *to which the individual is a party*. It appears from this language that a public defender (or for that matter, any defense counsel) would not be able to subpoena medical records of a person who was the victim of a crime since such victim would not strictly speaking be a "party" to the litigation. (Similarly, a plaintiff or defendant engaged in civil litigation would be precluded

by this requirement from having the medical records of relevant third parties subpoenaed.) Therefore, it is suggested that the phrase "to which the individual is a party" be stricken from the section. A corresponding modification is recommended for section 104(b)(14) of H.R. 3444 which contains the same restricting language.

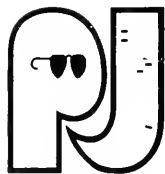
Finally, in order to forestall any possible confusion with respect to the applicability of the requirements in section 141 of H.R. 2979 and section 205 of H.R. 3444 to a federal public defender who attempts to obtain the medical records of an individual pursuant to a judicial subpoena, we would also like to suggest that the courts of the United States be explicitly excluded from the definition of "government authority" in section 101(5) of H.R. 2979 and of "Federal authority" in section 310(4) of H.R. 3444. Since public defenders are federal employees, it is conceivable that they would be viewed as employees of a federal authority and as such might be denied access to medical records unless they complied with the government access provisions of the bills. If subject to such access provisions, federal public defenders would then be operating under different procedures from those followed by appointed or retained private attorneys. It would be undesirable to create a situation wherein a different form of representation is rendered purely on the basis of the fact that appointed counsel is a federal employee. Also, since it is relatively clear to us that it is not in fact your intent that a public defender be subject to the same restrictions and requirements applicable to a government authority seeking medical records pursuant to a "law enforcement inquiry," we feel that this additional clarification would be helpful.

Your consideration of the above comments and suggestions is appreciated. If I can be of any further assistance, please let me know.

Sincerely,


William E. Foley
Director

B. LETTER FROM ROBERT ELLIS SMITH, PUBLISHER,
PRIVACY JOURNAL



PRIVACY JOURNAL

P.O. Box 8844
Washington, D.C. 20003
(202) 547-2865

an independent monthly on privacy in a computer age

May 8, 1979

ROBERT ELLIS SMITH
Publisher

Richardson Preyer, Chairman
House Subcommittee on
Government Information
Rayburn Bldg. B371
Washington, D.C. 20515

Dear Rep. Preyer,

I want to commend you for your proposal to protect the privacy of medical records, HR 2979. Clearly a majority of the American people view medical records as the most important area needing legislative protection right now, and your bill is generally well drafted.

I hope that you will reconsider Section 128, which would permit access to patient information by the Secret Service, and Sec. 129, which would permit access by law enforcement authorities, each without legal process. Either section would be acceptable if the information disclosed were limited to the location, time of admission and general condition. Additional medical information is too sensitive to be disclosed without consent or legal process. As drafted, Sections 128 and 129 would permit greater access to medical information than is generally recognized as proper under current law and ethical codes.

This is why I feel that the Administration's bill, HR 3444, is not an improvement on current law, except in Sections 101, 102 and 301. HR 3444, as drafted, includes more than 60 instances when sensitive patient information may be disclosed to outsiders without the consent of the individual. This is contrary to the current expectation of privacy and contrary to the ethical tradition among health care professionals. I urge you to tighten up, or delete, Sections 128 and 129 of HR 2979 and work for its passage.

This is important legislation and you and the subcommittee staff are to be commended for your proposal.

Yours truly,

Robert Ellis Smith

C. LETTER FROM ARTHUR GOSHIN, M.D., PRESIDENT, HEALTH CARE
PLAN

Health Care Plan

Good Health for Western New York

May 8, 1979

MAY 11 1979

Congressman Richardson Preyer
2344 Rayburn Office Building
Washington, D. C. 20515

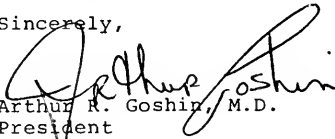
Dear Congressman Preyer:

I am writing to express my concern about two bills, HR 2979 and S503, related to privacy of medical records. As presently written, these bills would do very little to enhance privacy of the individual's medical record and would jeopardize the use of the medical record as legal documentation of the physician's evaluation and/or actions. We share the public's concern that medical records must be kept private and confidential, however, we also feel that the most effective safeguards should be directed at which organizations and individuals other than the patient have a right to see records and under what circumstances. Furthermore, an important balance must be achieved between the use of the medical record as the physician's legal document and the patient's need for a record of his health experience or status.

It is generally accepted in the medical community that medical records contain a substantial amount of technical information which is not readily understandable by the public. What types of "corrections" might be envisioned by Section 112 of the bill are vague and could only lead to administrative and professional complexities without attendant benefit. This is not to say that patient's should be prohibited from viewing their records or from obtaining summaries of relevant information. In fact, several demonstration projects involving patient-held records have shown positive provider and patient acceptance of brief medical summaries which the patient could retain for future use of general information. In addition, mental health records are particularly problematic. Subjective comments or impressions would be especially prone to contention. In addition, any requirements on institutional providers would have limited impact as they would not affect private practitioners who dominate ambulatory care services delivery.

In summary, the emphasis of any privacy bill should be on assuring that provider organizations operate with reasonable procedures regarding the release of medical records and that specific requirements restrict the occasions on which outside organizations can obtain medical record information.

Sincerely,



Arthur R. Goshin, M.D.
President

ARG/eap

CC: GHAA

**D. LETTER FROM BOYD THOMPSON, EXECUTIVE VICE PRESIDENT,
AMERICAN ASSOCIATION OF PROFESSIONAL STANDARDS REVIEW
ORGANIZATION**



AMERICAN ASSOCIATION OF PROFESSIONAL STANDARDS REVIEW ORGANIZATIONS

11325 SEVEN LOCKS ROAD • SUITE 214 •
POTOMAC, MARYLAND 20854 • 301/983-0404

May 23, 1979

MAY 28 1979

The Honorable Richard Preyer, Chairman
Committee on Government Relations
Rayburn House Office Building
Room B-349-B-C
Washington, D. C. 20515

OFFICERS

President
Harry S. Weeks, M.D.
Charleston, W.V.

Vice-President
George P. Lecht, M.D.
Cleveland, Ohio

Secretary
James Byrne, M.D.
Miami, Florida

Treasurer
James Pillock, M.D.
Laurens, New Hampshire

Past President
John Bussman, M.D.
Portland, Oregon

DIRECTORS

Anthony Abbot, M.D.
New York, New York

Robert Becker, M.D.
Joliet, Illinois

George Bryden, M.D.
Albuquerque, New Mexico

Andrew J. Cascone, M.D.
Hartford, Connecticut

Frederick C. Dill, M.D.
Minneapolis, Minnesota

Robert Fathan, M.D.
Seattle, Washington

George Hester, M.D.
New York, New York

Alan Nelson, M.D.
Salt Lake City, Utah

Daniel O'Regan, M.D.
Trenton, New Jersey

M. Frank Seltzer, M.D.
Raleigh, North Carolina

John M. Wasserman, M.D.
Torrance, California

John Wood, M.D.
Englewood, Colorado

Bill Mahon, Ex-Officio
Columbus, S.C.

Speaker of the House
Kenneth Platt, M.D.

Vice-Speaker of the House
Jim Pillock, M.D.

Dear Mr. Preyer:

Thank you so much for your letter of May 2, 1979 asking for our comments on H.R. 3444 and H.R. 2979, the "Privacy of Medical Information Act" and the "Federal Privacy of Medical Records Act" respectively.

The American Association of Professional Standards Review Organizations, which represents 186 Professional Standards Review Organizations in the nation, takes the general position that the medical records of patients should be kept as confidential as possible consistent with sound public policy. More specifically, we wish to make the point that it is necessary in the course of their Federally mandated work in the review of the quality and cost effectiveness of health services furnished to Medicare and Medicaid patients for PSROs to examine individual medical records. H.R. 3444 recognizes this directly in section (b)(6) by permitting such information to people who "need the information to carry out a program under...part B of Title XI...of the Social Security Act...".


H.R. 2979 does not include a direct reference to the PSRO program. It would, however, permit disclosure under section 125(a)(1) if "the disclosure is for the purpose of an audit or evaluation." The term "audit" would be defined under section 101(2) of the bill, but the language is to be supplied.

We understand from your able staff person, Mr. Robert Gellman, that it is the intent of the bill to permit disclosure to PSROs and that the language of section 101(2) will do so. Since it is absolutely essential to a PSRO that medical and other information on patients held by the provider of health services be made available, we suggest either that a separate section of the bill specifically authorize such disclosure or that the term "audit" in section 101(2) specifically include the range of activities required or permitted to be performed by PSROs under part B of Title XI of the Social Security Act. In any bill reported out by the subcommittee we would strongly urge this specific approach.

Specific provisions of present law (and regulations issued under the law) prohibit disclosure of patient information held by PSROs, and we would propose that those provisions remain in effect and not be superseded by other legislation. The existing provisions have proven workable and have clearly protected patient rights to privacy. To substitute other provisions at this point would introduce confusion and delays without improving the desired protection.

We appreciate very much your request for our reactions; hopefully our suggestions will be helpful in working out solutions to a complex, but very important set of issues.

Sincerely,

A handwritten signature in cursive script that reads "Boyd Thompson".

Boyd Thompson
Executive Vice President

BT/ms

E. LETTER FROM CHRISTOPHER C. FORDHAM III, DEAN,
UNIVERSITY OF NORTH CAROLINA MEDICAL SCHOOL



MAY 29 1979

THE UNIVERSITY OF NORTH CAROLINA

AT

CHAPEL HILL

21 May 1979

Office of the Dean
The School of Medicine

The University of North Carolina at Chapel Hill
MacNider Building 202 H
Chapel Hill, N.C. 27514

The Honorable Richardson Preyer
House of Representatives
Rayburn House Office Building, Room B-349-B-C
Washington, DC 20515

Dear Congressman Preyer:

I appreciate your letter of May 2 and the attached Bills H.R. 2979 and H.R. 3444. After consultation with colleagues, we have serious concerns about both bills. Although they appear to regularize access to medical records and authorize legitimate research under a set of rules, there are three features about which we are profoundly concerned. The first is what appears to be the absolute right of the patient to have access to the medical record; this will very likely reduce the validity of the record and impair patient care. Medical records will become a less useful way to communicate vital clinical information, and what appears to be a well intentioned effort to improve "justice" will likely impair the quality of patient care. Secondly, the right of the patient to make corrections in his own record almost suggests that the patient could change his diagnosis. This is a terribly complicated issue; so many patients refuse to accept a considered professional opinion for literally years; it would appear to offer the real potential for a blizzard of paper work, and little improvement, if not deterioration, in the quality of patient care. Third, the right of the FBI, the CIA, the Secret Service and governmental agencies to have access to a medical record without consent of the patient. This is distasteful to us and we would oppose it. The medical records should not be made an instrument of government policy or government security. These records are primarily intended to assure, insofar as possible, quality medical care and to serve the well-being of the patient. If that instrument is to be made available to governmental agencies for purposes unrelated to patient care, we surely will have a new set of problems on our hands.

While there are many understandable and presumably laudable features about these two bills, the above concerns lead us to believe that further deliberations should be undertaken before they are subjected to a process which might enact them into law.

My guess is that we are not very helpful to you, but we have tried, and we send along our warmest best wishes.

Sincerely yours,

Christopher C. Fordham, III, M.D.
Dean

F. LETTER FROM JEROME S. BEIGLER, M.D., CLINICAL PROFESSOR OF
PSYCHIATRY, UNIVERSITY OF CHICAGO

JEROME S. BEIGLER, M. D.
2424 PRUDENTIAL PLAZA

CHICAGO, ILLINOIS
60601

MAY 29 1979

May 24, 1979

The Honorable Richardson Preyer
Chairman
Government Information and Individual
Rights Subcommittee of the Committee
on Government Operations
Rayburn House Office Building, Room B-349-B-C
Washington, D.C. 20515

Re: H.R. 2979
H.R. 3444

Dear Congressman Preyer:

I am pleased to respond to your invitation for comments regarding H.R. 2979 and H.R. 3444 to supplement my testimony before your Subcommittee on April 9, 1979. In general, although both bills are similar, I find "Section 102, Effect on State Laws" of H.R. 2979 much preferable to the provisos in H.R. 3444 regarding supersession of State and local laws, protection of alcohol and drug abuse records and particularly psychiatric and mental health treatment records. Provisos for access to their records by patients also are commendable.

Otherwise I find both bills incompatible with the principles of a democratic government. Access is provided to medical records without due process to law enforcement agencies as well as to many other agencies. There seems to be a complete disregard for the necessity of providing a circumstance of professional confidentiality for the communications between patient and physician and particularly between patient and psychiatrist. Without such provisos treatment cannot be accomplished any more than a surgeon can perform his operations in a non-sterile field. Preventing access to treatment for our citizens is not in the interest of society or our political system. The constructive legislative work in such jurisdictions as the State of Illinois and also in Washington, D.C., which have balanced confidentiality statutes, would be largely undermined if H.R. 2979 and/or H.R. 3444 were enacted.

It causes me considerable bewilderment when I read the titles of these bills as "Privacy" acts; whereas in reality these are "Discovery" bills.

I must refer again to my testimony before your Subcommittee on April 9, 1979 in which I point out that these bills which allow such unrestricted access to medical records by law enforcement and other agencies are further pieces of evidence that our democracy is in the middle of a third wave of recent ultraconservatism previously manifested by the Joe McCarthy problem and the Nixon disgrace.

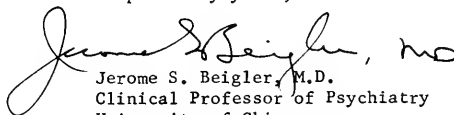
I am well aware of your legislative responsibility to provide for the monitoring of cost-effectiveness and abuses of expensive medical treatment. I believe this can be done while at the same time enabling treatment in a prerequisite circumstance of real privacy. Examples of such legislation in Illinois as well as that of the American Psychiatric Association's Model Law on Confidentiality were submitted to your staff on April 9, 1979.

My recommendations regarding privacy of medical records legislation are as follows:

1. Modification of Federal legislation to approximate the Illinois statute or the APA Model Law.
2. Provide that State law supercedes when it protects privacy more stringently than does Federal law.

I regret I must call these problems to your attention, but I feel our whole system of government is at stake.

Respectfully yours,

A handwritten signature in dark ink, appearing to read "Jerome S. Beigler, M.D.", with a stylized flourish at the end.

Jerome S. Beigler, M.D.
Clinical Professor of Psychiatry
University of Chicago
Pritzker School of Medicine

G. LETTER FROM W. G. ANLYAN, M.D., DUKE UNIVERSITY MEDICAL
CENTER



DUKE UNIVERSITY MEDICAL CENTER

Vice President for Health Affairs

May 20, 1979

MAY 28 1979

The Honorable Richardson Preyer
Congress of the United States
2344 Rayburn House Office Building
Washington, D. C. 20515

Dear Rich:

Thank you for your letter of May 2 and the request for us to suggest comments on H.R. 2979 and H.R. 3444. I have depended principally on our legal counsel, Mrs. Patricia H. Wagner, who, along with her staff, is an integral member of our team in the Medical Center. Pat has had vast experience "in the trenches" of our complex hospital, as well as previously at UNC Memorial Hospital in Chapel Hill.

Pat has gone over H.R. 2979 with a fine tooth comb. I am enclosing her comments which I have read and with which I concur. She has also been in touch with Bob Gellman of your staff.

In your letter of May 2 you suggested that though there was no deadline, a fast turnaround would have greater impact. It is for that reason that I am sending this response to you and at the same time distributing an additional copy to Ike Robinson, Associate Vice President for Health Affairs and Chief Executive Officer of Duke University Hospital. Ike has been attending an international nephrology conference in Paris and should be back this week. If he and his staff have any additional comments, we will relay them to you.

We are most appreciative of the opportunity to have input into these important pieces of proposed legislation.

Best personal regards and every good wish.

Sincerely yours,

Bill

W. G. Anlyan, M.D.

WGA:jb

cc: Dr. R. R. Robinson

Duke University Medical Center

DURHAM NORTH CAROLINA 27710

ASSOCIATE UNIVERSITY COUNSEL

TELEPHONE (919) 684-6099

P. O. BOX 2901

May 16, 1979

MEMORANDUM TO: William G. Anlyan, M.D.
Vice President for Health Affairs

FROM: Patricia H. Wagner *P.H.*
Associate University Counsel
for Health Affairs

RE: Comments on H.R. 2979, An Act to
Protect the Privacy of Medical Records

This bill is basically well-written, and I am in agreement with the substantive provisions. The procedures it mandates for patient access to records are essentially those already in effect at Duke Hospital. I am concerned, therefore, that perhaps the bill is unnecessary and will add another layer of federal regulations, increase in HEW workload and hospital administrative workload, with concomitant increases in both tax expenditures and hospital costs--all for very little gain. I would suggest a careful study of the need for such a bill first.

My experience with the American Association of Hospital Attorneys would indicate that hospitals are increasingly aware of patients' rights to see their medical records; doctors write in the records now with the expectation that patients will see them (except for the clearly recognized narrow "therapeutic exception" applicable mainly to psychiatric patients); and that the increase in malpractice litigation is solving this problem without federal legislative intervention.

The two areas where legislative clarification is needed are those of (1) health research using medical record data (Section 124) and (2) the facility's right to override physician/patient privilege in order to warn of imminent danger (Section 126). If the bill could be passed without substantially increasing the federal regulatory burden on hospitals, it would be worthwhile. I believe this could be done by private enforcement under Section 153, thus making administrative regulations and enforcement procedures unnecessary.

Specific comments on the bill follow:

Page 7: Lines 13 and 17--"supersedes" is misspelled.

- Page 8: Part B--"Rights of Access, Correction and Notice," is reasonably and fairly written to protect the patients' rights without undue hardship on the facility.
- Page 11: Section 113(b)--The notice requirements are fairly onerous. As a practical matter, the facility will have to notify every patient at every visit because of the difficulty of keeping records of who had been notified when. As an alternative, such notice could be published once a year or posted at the facility along with Hill-Burton notices.
- Section 113(c)--I would suggest a short model notice in the bill itself as an alternative to promulgating more regulations.
- Page 12: Section 114(2)--What constitutes "proper" identification? Spell out in the bill rather than by regulation.
- Page 13: Section 121--The provision for disclosure to an employee of the facility "who has a need for [it] in the performance of his duties" is an important provision and absolutely necessary for an effective risk management program to prevent recurrence of patient mishaps, among other things.
- Page 14: Section 124--Allowing medical record research is also very important. This may be the most needed part of the bill since there is currently great confusion about what research is legally permissible.
- Page 15: Section 124(b)--The requirements to protect the confidentiality of such research are all necessary and reasonable.
- Page 16: Section 124(c)--Again requires unnecessary additional work by HEW. Institutional Review Board oversight as required in Section 124(a)(1) ought to be sufficient. The IRB can prepare a notice describing the conditions in subsection (b), and compliance can be effected by HEW's control over the IRB's. The same comment applies to Section 132(b)(1) on page 25.
- Page 18: Section 126--Permitting the facility to disclose a medical record if necessary to protect persons or property from "imminent danger of serious" harm is also helpful. It resolves the current dilemma physicians face between protecting patient confidentiality and preventing harm to others subsequent to the Tarasoff decision in California.
- Page 21: Section 129--"Law Enforcement Functions," is needed since hospitals are often caught between demands of law enforcement

investigators and confidentiality requirements. I am not sufficiently informed about criminal investigation procedures to comment on the effectiveness of this section in weighing the balance between police needs and protection of individual rights.

Page 25: Section 132(b)(1)--See previous comment on Section 124(c).

Section 132(b)(2)--"Guidelines" for "accounting" procedures are unnecessary, time-consuming and costly. Section 101(1) is sufficiently clear for a medical care facility to comply without guidelines. Each facility can best determine for itself how to comply "inexpensively and with minimal disruption to the medical treatment process..." The statutory mandate is sufficiently clear to effect compliance. The threat of civil suit under Section 153, page 33, is also compelling reason for facilities to comply with the statute.

Page 35: Section 302--Once again, I would strongly recommend that regulations be kept to a minimum and that their requirement be eliminated from this bill wherever possible.

PHW:jch

H. LETTER FROM DONALD A. BRENNAN, EXECUTIVE VICE PRESIDENT,
GROUP HEALTH COOPERATIVE OF PUGET SOUND



**Group Health Cooperative
of Puget Sound**

MAY 29 1979

200 - 15th Avenue East • Seattle, WA 98112 • (206) 326-6262

May 23, 1979

The Honorable Richardson Preyer
Chairman
House Government Operations Subcommittee on
Information and Individual Rights
The United States House of Representatives
2344 Rayburn
Washington, D.C. 20515

Dear Mr. Preyer:

Two bills have been introduced this legislative session which attempt to guarantee the right of an individual to inspect his or her medical record, to seek correction of information contained in that record believed by the individual to be erroneous, and to restrict access to that record to necessary inspection for a defined purpose. As the health care provider for some 265,000 individuals and a major provider of health care in the Puget Sound area, Group Health Cooperative of Puget Sound has sought to establish policies affirming these same objectives. On behalf of the Cooperative, however, I do want to express to you some concerns and suggestions which my staff and I have raised after reviewing the bills in some detail.

Although your committee markup concerns only one of the bills, my comments address provisions in both H.R. 2979, the proposed "Federal Privacy of Medical Records Act," and S. 503, the proposed "Privacy Act Amendments of 1979." The two documents incorporate the same major objectives, with slight variations noted throughout.

The "Findings and Purposes" of both bills specifically outline laudable goals and, in most instances, reasonable findings. I am not entirely in agreement with Sec. 2(a)(4) of H.R. 2979. That subsection finds that "medical information about an individual is routinely made available to public and private organizations for uses not directly related to the provision of medical services to the individual." I would be particularly interested in learning of data or studies substantiating this finding. I am unaware of evidence of the widespread abuse of the numerous controls on access to information, including state law, standards established by the Joint Commission on the Accreditation of Hospitals, Federal regulations concerning access to Professional Standards Review Organizations' files, and others.

Section 101.(10) of H.R. 2979 defines the term "medical record" in a manner not consistent with the standard definition made by the courts of information subject to the privilege of confidentiality. The definition normally includes any information acquired by a physician while attending a patient, which was necessary to enable the physician to prescribe or act for the patient. This may include narrative accounts of the cause of an injury if those statements are necessary to obtain professional advice or treatment. I would note that the definition used in S. 503, a bill proposing "to provide for the confidentiality of medical records" (page 1, line before No. 1) is even less appropriately defined and does not restrict applicability to medical records.

The bills' disparate definitions of the age at which an individual can begin to exercise rights both introduce conflict with existing law and precedent. The Senate proposal identifies a minimum age of 12 years (Sec. 205), which precedes the age of 13 established by common law and historically by statutes allowing assumption of certain responsibilities such as signing contracts. Our policies stipulate the age of 13 with the caveat that a physician raising serious questions of the patient's maturity may limit that access. The House proposal, on the other hand, prohibits the individual's right to control access until the age of majority of the local jurisdiction (Sec. 103). This also conflicts with state, and perhaps Federal, statutes and judicial findings regarding the rights of minors to keep records of, among others, drug addiction, abortion, sterilization, and alcoholism confidential.

Section 111(a) provisions of H.R. 2979 do appear consistent with our state law and Cooperative policy, although we prefer a written request for access to allow us to verify the identity of the source and to have a record of the request. Section 111(b) does not specify standards for the process of denying a request (i.e., whether a written notice of the reasons for denial is required, the appeal process). Both bills allow individuals refused access to their record the right to designate a representative to review the record for them. Within the Cooperative we have reserved the right of the physician to raise objections to granting access to the designee under certain conditions. We also have the physician discuss with the designee why the Cooperative felt the patient should not read the record and what suggestions we might provide as to how the designee might relay the contents to the patient.

The provisions relating to correction of medical records (Sec. 112 in the House version, Sec. 203(b) in the Senate version) are consistent with a national trend prompted by recent studies in this area. While Group Health's present policy allows for inclusion of a statement of disagreement by the patient rather than correction of the record, we are currently considering a recommendation to include such a provision.

The restrictions on release of information for medical research reflect a reasonable approach, one we use throughout our organization. We do prefer the wording of the House version specifying that the facility "remove, where practicable, information enabling individuals to be identified" (Sec. 124(a)(2)).

In trying to review and compare the exemptions to the confidentiality provisions, we found the language of both bills unclear as to the status of state laws and under what circumstances statutes might be superseded. Certain exemptions, some of which are state mandated, are not noted in one or the other bill. These include disclosure for a death requiring investigation by the Medical Examiner's office, identification of the deceased, workman's compensation cases, and communicable diseases. Indeed, it is essential that governments and agencies be able to fulfill their statutory duties under the applicable laws. These exclusions, and any others that may exist, should be clearly identified and not superseded. Furthermore, the need justifying the release of information and the conditions for that release ought to be consistent for all exemptions.

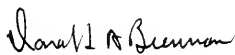
The statements of objectives introducing both bills promote the concept of informing individuals when anyone gains access to that individual's medical record. The stipulation that no one may inform an individual if "a government authority has sought or obtained access to a medical record" (Sec. 128.b. of H.R. 2979 and Sec. 211.(a)(3) of S. 503) contradicts those objectives as well as recent efforts to allow individuals' access to information collected and maintained by government agencies.

Although, as my foregoing comments indicate, the policies and procedures observed within our Cooperative do not differ markedly from those proposed in either bill, I would raise the concern that this may not be the case in all health care institutions or even in all health maintenance organizations. For many of the specific reasons I have given, implementation of either program may require amendment of state and local laws, adoption by institutions of new policies and development of corresponding procedures, and clarification of the intricacies of the final law. Clearly this will require substantial, time-consuming change. I would question, therefore, the unduly restrictive and unrealistic period for compliance of six months specified in both documents. Additionally, the Senate version's requirement that the Secretary promulgate all final regulations two months prior (or four months after passage of the legislation) to that date severely taxes the likelihood that comprehensive, reasonable regulations could be developed, and may even run contrary to the required periods for issuance of proposed regulations, required comment periods, and issuance of final regulations. Certainly the ability of the Secretary to review the comments likely to be generated by such regulations and, where deemed appropriate, to develop revised regulations reflecting the public response would be severely hindered.

These last concerns raise yet another more basic question of the appropriateness of Federal intervention in the area of assuring confidentiality of medical records, especially in the detail and degree outlined in the two bills under consideration. As I have noted previously, the privacy of medical records is already subject to protection and strict regulation by several sources. The Federal government recognizes accreditation of facilities under JCAH standards as sufficient evidence of appropriate standards for confidentiality of medical records for the purposes of the Medicare program. Similarly, state statutes mandate attention to confidentiality of records. Other sources can be cited. Indeed, without further justification for the need of Federal legislation, the procedures outlined portend costly, duplicative reporting systems and resource consumption to prove we are already doing what is being proposed. Furthermore, enactment of provisions in the degree of specificity suggested will prove extremely difficult to change, even if change proves absolutely essential, once they are passed in the form of Federal law. Should there be further justification presented for Federal control of access to medical records, I would at least caution the sponsors to present the specificity in regulations, not law. This would also assure representative expression of views on the other issues raised in this letter.

The issues I have identified indicate the concerns my staff and I raised after reviewing H.R. 2979 and S. 503. Clearly we do not disagree with the basic aims of assuring confidentiality of and carefully controlling access to patients' medical records. The specific provisions presented in the documents differ only in minor details from the policies we have developed for our Cooperative in our efforts to promote those aims. I would request, however, your consideration of the points expressed in this letter, and encourage you to contact me for any further clarification or input I might be able to provide.

Respectfully submitted,



Donald A. Brennan
Executive Vice President

cc: Group Health Association of America

I. LETTER FROM SEYMOUR JABLON, DIRECTOR, NATIONAL
RESEARCH COUNCIL

JUN 11 1979

NATIONAL RESEARCH COUNCIL
ASSEMBLY OF LIFE SCIENCES

2101 Constitution Avenue Washington, D. C. 20418

DIVISION OF MEDICAL SCIENCES
Medical Follow-up Agency

5 June 1979

Congressman Richardson Preyer
Subcommittee on Government Information
and Individual Rights
Room B-349C
Rayburn House Office Building
Washington, D. C. 20515

Dear Mr. Preyer:

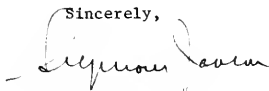
I am glad to have had the opportunity to review H.R. 2979, which you introduced on March 14, 1979 and H.R. 3444, introduced on April 4. The two bills, of course, address the same issues, and provide safeguards for privacy, while simultaneously attempting to insure that there will be no undue restrictions placed upon "health research projects".

Since our organization has been engaged for more than thirty years in epidemiologic and biomedical research studies, I am acutely sensitive to possible threats to the ability of research scientists to utilize medical records for purposes of obtaining epidemiologic information, which is not only useful to society but indeed essential for the safeguarding of public health. As an example, we are now engaged in a study of possible ill-effects which may have resulted among military personnel who, more than twenty years ago, witnessed tests of nuclear weapons at the Nevada Test Site or the Pacific Test Area. The requirement to obtain and review medical records for this, and other, studies needs no elaboration.

I was pleased to see that, under both bills, the needed records may be available. Frankly, however, it seems to me that the language of H.R. 2979, Section 101 (8) is far preferable to the language of H.R. 3444, Section 105 (b)(5)(A). The reason is that the latter, somewhat vaguely, places upon "the facility" the responsibility for determining that disclosure may be made; the former gives the responsibility, appropriately, to an Institutional Review Board. Our experience with the Privacy Act has demonstrated that even when disclosures are clearly permitted under the law and relevant Federal Register notifications, some individuals do not really understand the provisions of the law and the exemptions, and act on the principle that "If I do nothing I cannot be blamed." I am very fearful that some medical care facilities, especially smaller facilities that have little or no ongoing research, will know only that the privacy of medical records is protected and will be reluctant to "reasonably determine" that the requested disclosure may be made. At best, delays of several months can be anticipated while explanatory correspondence is exchanged.

Let me say that I do understand the problems that led to the drafting of legislation in this area. I am appreciative of the sensitivity to the needs of research displayed in both bills; I believe strongly, however, that the language of H.R. 2979 is far superior to that of H.R. 3444.

Sincerely,

A handwritten signature in cursive script, appearing to read "Seymour Jablon".

Seymour Jablon
Director
Medical Follow-up Agency

SJ/ces

J. LETTER FROM ELMA L. GRIESEL, EXECUTIVE DIRECTOR, NATIONAL
CITIZEN'S COALITION FOR NURSING HOME REFORM



National Citizens' Coalition for
NURSING HOME REFORM

1424 Sixteenth Street, N.W.
Suite 204
Washington, D.C. 20036
202/797-8227

Elma L. Griesel
Executive Director

Freide E. Gorrecht
President

June 19, 1979

JUN 25 1979

Representative Richardson Preyer
House Subcommittee on Government
Information and Individual Rights
B349 Rayburn House Office Building
Washington, D. C. 20515

Dear Representative Preyer:

We strongly support the efforts of your committee to develop a bill guaranteeing the rights of medical patients to personal access and confidentiality in regard to their medical records.

In particular, the right to inspect and amend, if necessary, one's own records would be an important step toward insuring quality of care for residents of long-term care facilities. At present, there is an inadequate system of review to assure that appropriate diagnostic and treatment procedures are utilized for this population. The result is that treatment generally addresses symptoms, rather than actual diseases and routine diagnostic procedures are not employed where appropriate. Treatment decisions by doctors are often not accompanied by personal visits to residents. Allowing access to medical charts by a resident or by his representative would help monitor diagnoses, treatments, and the authorizing personnel.

The Coalition is a national, non-profit membership organization, formed in 1975, to improve the long-term care system and the quality of life for nursing home residents.

We hope that you will give this legislation high priority and will consider the special needs of nursing home residents in determining its provisions. Please let us know if you need additional information or assistance.

Sincerely,



Elma L. Griesel
Executive Director

ELG/fb

K. LETTER FROM JAMES L. OBERSTAR, M.C., HOUSE OF
REPRESENTATIVES

JAMES L. OBERSTAR
8TH DISTRICT, MINNESOTA

ROOM 323
CANNON HOUSE OFFICE BUILDING
(202) 225-6211

DISTRICT OFFICE:
ROOM 231
FEDERAL BUILDING
DULUTH, MINNESOTA 55802
(218) 727-7474

COMMITTEES
PUBLIC WORKS AND
TRANSPORTATION
MERCHANT MARINE AND
FISHERIES
SELECT COMMITTEE ON
CONGRESSIONAL OPERATIONS

Congress of the United States
House of Representatives
Washington, D.C. 20515

June 28, 1979

Mr. Robert Gellman, Associate Counsel
Subcommittee on Government Information
and Individual Rights
Committee on Government Operations
B349, Rayburn Building
Washington, D. C. 20515

Dear Mr. Gellman:

I would like to bring to your attention a situation which I view as an invasion of privacy involving medical records.

One of the patients named on the attached surgery schedule has asked for my assistance on a disability claim. This schedule was included with other medical information substantiating the disabilities from which my constituent suffers. I am bothered by the fact that such explicit information is duplicated for circulation within any hospital, and even more concerned that it is available to any one of the patients.

I am well aware that I, too, am guilty of invading the privacy of these individuals by copying and forwarding this document to the Subcommittee for inclusion in the record of hearings on medical privacy. For this reason, I am withholding the name of the hospital or the community from which it came. I ask, however, that the Subcommittee attempt to determine how commonplace is the practice of posting and duplicating schedules of this type and what restrictions are placed on its dissemination.

Thank you for your attention to this request.

Sincerely,


James L. Oberstar, M. C.

JLO:mjy

SURGERY JAN. 23, 1976

HOUR	SURGEON	OPERATION	PATIENT'S NAME		RESIDENT	CASE NO	ROOM
			ANES	M.A.			
8:00	DR. DOBBS	T & A	M.A.	M.A.	---	411721	726
8:00	DR. BARTZEN	LAPAROSCOPY-POSS. TUBAL PLASTY	M.A.	M.A.	---	411723	384
8:00	DR. GROHS-W. RUDIE	BREAST BIOPSY-POSS. RADICAL	M.A.	M.A.	---	362110	385
8:00	DR. FIFIELD	T.U.R.	M.A.	M.A.	---	371997	605
8:00	DR. SCUKUP	L.T. HYDROCELECTOMY-RT. ING. EXPLORE-POSS. ORCHIECTOMY	M.A.	M.A.	---	411707	610
8:00	DR. SWEDBERG	DUFUYTREN'S CONTRACTURE FINGER	M.A.	M.A.	---	411722	371
8:15	DR. KUBISTA	TOTAL ESOPHAGECTOMY	M.A.	M.A.	---	318001	460
9:00	DR. DOBBS	T & A - MYR. WITH T.	M.A.	M.A.	---	411724	719
10:00	DR. DOBBS	M.Y.R. WITH T.	M.A.	M.A.	---	---	0-1
10:00	DR. GROHS	D & C	M.A.	M.A.	---	350879	390
10:00	DR. WILLIAMS	VAG. SUSPENSION UTERUS	M.A.	M.A.	---	363703	540
10:00	DR. DONLEY	LEFT BRACHIAL ANGIOGRAM	LOC. NA	LOC. NA	---	396397	611
10:30	DR. GROHS	ABDOMINAL EXPLORE	M.A.	M.A.	---	356990	445
11:00	DR. BARTZEN	D & C	M.A.	M.A.	---	---	0-1
11:00	DR. BGMAN	REM'L COMPRESSION PLATE FEMUR	M.A.	M.A.	---	381554	350
11:00	DR. DOBBS	ESOPHAGEAL DILATATION	---	---	---	---	NOT IN
11:00	DR. D. GOLDSH	D & C	M.A.	M.A.	---	362527	563
12:00	DR. BGMAN	REM'L BAKERS CYST-KNEE	M.A.	M.A.	---	409311	517
12:00	DR. DOBBS	EXPLORE TYMPANOPLASTY	LOCAL	LOCAL	---	---	NOT
12:00	DR. WILLIAMS	D & C	M.A.	M.A.	---	392064	300
12:00	DR. SCUKUP	CYSTO-POSS. T.U.R.-POSS. VASECTOMY	M.A.	M.A.	---	411716	400
1:00	DR. BGMAN	REM'L OSTEOCHONDROMA-RT. TIBIA	M.A.	M.A.	---	334596	100
1:00	DR. LARSON-HOOD	ONE EXT. 3 PARTIAL BONY IMPACTIONS	M.A.	M.A.	---	105403	475
1:00	DR. DOBBS	SINUS WASH-RT. NASAL ANTRAL WINDOW	LOCAL	LOCAL	---	400726	540
2:00	DR. BGMAN	RESECTION DISTAL CLAVICLE-LEFT SHOULDER	M.A.	M.A.	---	411720	360
2:00	DR. FIFIELD	CYSTO-POSS. RETRO-POSS. T.U.R.	M.A.	M.A.	---	343742	400
2:00	DR. BGMAN	BIOPSY HUMERUS HEAD	M.A.	M.A.	---	11584	---

L. LETTER FROM PHILIP H. TAYLOR, M.D., CHAIRMAN, PEER REVIEW
SYSTEMS, INC.

PEER REVIEW SYSTEMS, INC.

3720-J OLENTANGY RIVER ROAD • COLUMBUS, OHIO 43214 • (614) 451-3600

July 2, 1979

Mr. Richardson Preyer
Chairman, Government Information
and Individual Rights Subcommittee
Rayburn House Office Building,
Room B-349-B-C
Washington, D.C. 20515

Dear Mr. Preyer:

It has come to our attention that HR 3444 "Privacy of Medical Information Act" and HR 2979 "Federal Privacy of Medical Records Act" are being considered by the Subcommittee on Government Information and Individual Rights. Access and confidential disclosure of this patient information is critically important and essential for the future of the PSRO program if PSROs are to continue to fulfill their responsibilities as mandated in the PSRO law. In order to assist the Committee in reviewing these two bills, we wish to offer our comments on this important matter and its effect on the PSRO program.

Although HR 3444 Section (B) (6) recognizes the need for PSROs to have confidential access to patient medical records, HR 2979 "does not include a direct reference to the PSRO program." HR 2979 Section 125 (A) (1) does, however, authorize disclosure of information for the purposes of an audit or evaluation with specific definition language for audit to be supplied for under Section 101 (2) of the bill.

We have been informed that the intent of the bill is to permit disclosure to PSROs and that the language reiterating this will appear in Section 101 (2) of the bill.

Since access and confidential disclosure to patient medical records information is essential to the PSRO program, Peer Review Systems, Inc. would like to suggest a separate section of the bill be incorporated to specifically authorize such disclosure of patient information to PSROs and that the term "audit" in Section 101 (2) specifically include the range of activities required or permitted to be performed by PSROs under Title XI of the Social Security Act.

The PSRO Law (92-603) and supportive regulations to the Law specifically prohibit disclosure of confidential information held by PSROs. To disrupt these operational provisions at this time would have a significant adverse effect on the past and future contributions that the PSRO program has and can make.

Thank you for your attention in this important matter. If we may provide you with additional information, please do not hesitate to call upon us.

Sincerely,



Philip H. Taylor, M.D., Chairman
Board of Trustees

PHT/clb

cc: Senator John Glenn
Senator Howard M. Metzenbaum
Representative John Ashbrook
Representative Clarence J. Brown
Representative Samuel Devine
Representative William H. Harsha
Representative Chalmers Wylie
Harry S. Weeks, M.D., AAPRO
Peer Review Committee

M. LETTERS FROM IRWIN N. PERR, M.D., J.D., PROFESSOR OF PSY-
CHIATRY, COLLEGE OF MEDICINE AND DENTISTRY OF NEW
JERSEY



COLLEGE OF MEDICINE AND DENTISTRY OF NEW JERSEY

RUTGERS MEDICAL SCHOOL
University Heights
Piscataway, New Jersey 08854
Institute of Mental Health Sciences

Department of Psychiatry
(201) 463-4439

Community Mental Health Center
July 10, 1979

Richardson Preyer, Chairman
Government Information and Individual
Rights Subcommittee
Committee on Government Operations
Rayburn House Office Building, Room B-349-B-C
Washington, DC 20515

Dear Mr. Preyer:

I am responding to your letter of May 2, 1979 asking for comments on two proposed bills, H.R. 3444 and H.R. 2979. I was contacted because of my position as President of the American Academy of Psychiatry and the Law. Inasmuch as the content of these bills deals directly with areas of my professional activities as an educator, lawyer, and psychiatrist, I am pleased to respond with the caution that I do so in my individual capacity. I cannot speak on behalf of the Academy without review by our Executive Committee of the content of this letter. This matter will be referred to the Executive Committee at its next meeting in October, 1979 in Baltimore.

A review of these rather complex bills is a complex task, particularly in view of its very complicated language. Although many states have privilege and confidentiality statutes, few have statutes as detailed and potentially cumbersome. The very language constitutes a burden to communication and understanding.

I must first state my strong belief that professional medical practice and care are enhanced by the protection of privacy and that physicians must never lose their primary responsibility to patients for patient care. They cannot do that and act as agents to enforce social tranquility.

I will first methodically discuss H.R. 3444. While the bill states under "Findings" that the purpose of the act is to provide privacy and control over confidential medical information

for the individual, the stated policies and various ambiguities raise a question as to whether this goal would indeed be met. I note that there is a statement that all health care providers affect interstate commerce; I trust that this was interposed to allow for a claim of federal jurisdiction. Whether this is so in reality is questionable.

The section entitled "Access to Medical Information" raises separate issues. Unlike H.R. 2979, the bill does not give special attention to psychiatric or mental health procedures. I am unclear as to the type of situations to which the section, Correction of Medical Information, applies but it would seem inappropriate in a privacy statute.

Section 104 allows for disclosure only to the extent needed to accomplish the purpose for which the disclosure is made. What does this mean? Who is to decide this? Does it have any real meaning? It clearly does not, as stated in Sec. 104, in disclosures to Federal or State authorities.

Section 105 (b) (2) may provide problems in that it would now allow for psychiatric information to be given to other health providers without control by the individual. It, of course, would apply to other matters, e.g., allowing obstetrical or urological information to be disseminated that a person might not wish made available to other health providers.

Sec. 105 (b) (5) (C) (ii) allows for disclosure, in a research or statistics project, to prevent a crime. Does this have practical meaning? The very idea of preventing crime by using medical or scientific informers is probably more wishful thinking than practicality. In this type of situation, it seems bizarre.

In Sec. 105 (b) (5) (c) (iii) (II) and (III), who is the party to do the publishing that has the responsibility?

Sec. 105 (b) (7) (A) and (B) requires the recipient to assure a medical care facility as to certain criteria for its use of records. What meaning does this have to a medical care facility that has once released information? Why are agencies dealing with payment allowed to use this information "in compelling circumstances affecting the health or safety of the individual or another person" (Sec. 105 (b) (7) (B) (ii)?

Sec. 105 (b) (9) is vague. To what does it refer?

Sec. 105 (b) (11), (12), (13), (14), (15), (16), (17), (18), (19), and (20) all raise momentous questions. For example, under (17) if an officer in the American uniformed services wishes to see a private psychiatrist in a medical care setting or individually in the military setting (Sec. 202[16]) about a domestic or sexual problem, why is there a justification for breach of privacy? Sec. (18) would be satisfactory if the person were informed originally that communications would not be confidential. The possibility of psychotherapy otherwise would severely be affected. These various exceptions and the potential secrecy (suppression of the fact of release) more than anything else clearly vitiate the intent of the act in protecting privacy.

While I do not particularly object to Sec. 108, I can see that attorneys might object to what they perceive as reasonable preparation of their cases. On the other hand, the opening up of such information could minimize the likelihood of fraud.

Title II, while entitled "Requirements Applicable to Government Authorities," deals more with Health Care Providers, rather than Medical Care Facilities. I assume that this covers both institutional facilities and physicians' private offices. It includes many of the provisions already discussed. In particular, Sec. 202 (8), (9), (10), (11), (12), (13), (14), (15), (16), (17), and (18) provide numerous exceptions to the concept of privacy.

The requirement for "legitimate law enforcement inquiry" is certainly quite loose and can allow for both fishing expeditions as well as access to "legitimate" materials. Either situation raises serious policy issues. The bill, Sec. 210, also allows for transfer of information between various governmental entities--another potential problem.

Looking at H.R. 3444 more broadly, it is clear that the act is not in fact a privacy act, but rather a bill that would allow for an unbelievably aggressive violation of the principles of confidentiality and privilege which have been so laboriously gathered under the law, state by state, in the attempt to maintain individual rights. It would indeed accomplish the opposite of its purported purpose.

Let us look for a moment at the everyday world of practicality. The major areas that require protection in order to

encourage access to reasonable professional care deal with personal injuries, domestic relations, custody, and criminal matters. Many of these matters involve psychiatric issues--particularly the latter three. Many states that have privilege statutes will not allow investigation of medical records in possible criminal matters. Certainly persons with behavior problems or criminal records (whether on probation or parole or otherwise) will be hampered in communicating or discussing their problems or learning new modes of behavior. Already the perceived use of the psychiatrist as informer is not compatible with professional function. Similarly the misuse of medical, including psychiatric, information has been sufficiently catastrophic in domestic relations and custody cases as to seriously affect therapy. Even minor exposures can cripple public careers. The most onerous aspect of the proposed bill is the elimination of privacy in relation to the government itself. This bill, by superceding state law, would in many states, result in a very severe loss of privacy. Rightfully citizens would be fearful of expressing their thoughts or recounting their behaviors in professional consultation. I will not belabor this obvious point further other than to reassert that the bill is a regressive act that gives almost unbridled power to the greatest potential abuser--government itself.

H.R. 2979 is a somewhat simpler bill similarly dealing with the goal of protecting privacy. In its "Findings and Purposes," it is stated that "medical information about an individual is routinely made available to public and private organizations for uses not directly related to the provision of medical services to the individual." I would be curious as to the source of this statement and its meaning. What are the actual abuses to be corrected or avoided? One actual new issue is the problem of information in a centralized computer bank and who controls it. The concern over research data seems not to be much of a problem in the real world. The idea of individuals inspecting and correcting records similarly is confusing. What have been the alleged abuses? By what standard does any individual "correct" his medical record?

If in fact there were to be an adequate federal privacy statute, then one might reasonably raise a question as to why separate restrictions under the various alcohol and drug acts should be maintained. I see no reason for justification for such special status. The provision to allow for federal or state rules for confidentiality for psychiatric treatment is a

very important one, one which renders this bill far superior to H.R. 3444. Many physicians feel, however, that general medical practice requires such protections and that therefore additional protections given by state law to physicians at large should be maintained.

Interestingly though H.R. 2979 recognizes a unique quality in psychiatric or mental health treatment, it does not do so in regard to the records for such evaluation or treatment. The problem of inspection goes beyond mere possible harm. Records include complex special tests with unique language, interviews with families or other parties, the product of the physician's thinking, etc. Are these truly to be considered information owed to the individual? In any event, the question of right of access and correction (of what?) is somewhat different from the need for privacy. I continue to be curious as to actual alleged abuses dealing with "incorrect" material.

Sec. 130 opens up medical records to all litigation, civil and criminal. Similarly, under Sec. 131, almost any type of governmental inquiry will open the door. As under H.R. 3444, the government can obtain information secretly for a prolonged period.

H.R. 3444 has two sets of regulations, one for medical care facilities and one for health care providers. This distinction and redundancy makes no sense. On the other hand, H.R. 2979 seemingly applies only to a medical care facility; the status of the individual physician is unclear.

Though H.R. 2979 is much more clear compared to the monstrous verbiage of H.R. 3444, it shares with H.R. 3444 the problem of lack of protection against the prime potential abuser--the government itself, and would eliminate the protections present in many states that are far superior to that in the proposed federal bills. Ironically, the only protection left to the states is for alcohol and drug abuse programs. It is worth repeating that Sec. 102 (b) (3) acknowledging state laws protecting psychiatric or mental health treatment is a most important difference from H.R. 3444.

Because of the unbridled power given to government, both bills pose a risk to adequate care and individual rights.

These comments are generally quite negative in tone. H.R. 2979 is a better bill than H.R. 3444 for the reasons mentioned.

In addition, the authors of H.R. 3444 should be castigated for their circumlocutory abuse of the English language.

A reasonable privacy bill should deal with clearcut issues and state principles in a simplified, understandable fashion.

The bill should spell out a general principle favoring confidentiality in medical communications. Physicians see themselves in a position similar to attorneys and clergymen in protecting those for whom they are fiduciaries. This standard of privacy goes back thousands of years in medical custom. Our predecessor, Hippocrates would not take kindly to what the proponents of these bills would attempt to do.

A bill should state that all communications for treatment and diagnosis for that purpose shall be confidential and not be released outside a health care facility without written authorization by the patient or one empowered to act on behalf of the patient except:

(1) to accomplish involuntary psychiatric hospitalization or evaluation to weigh the necessity for such

(2) to inform relatives, next of kin, or appropriate parties about the general condition of the person

(3) to intervene in emergency situations where there is a significant threat to life or property, the discretion being that of the care provider

(4) to aid in the settlement of will cases where there is an issue as to competency

(5) as reasonably necessary for medical and statistical research

(6) as reasonably necessary to establish the basis for payment by third parties or to establish conformity to government supported programs

(7) to report those diseases stipulated by law for public health purposes

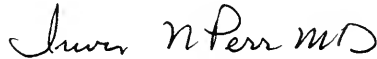
(8) in civil litigation where the patient is a party, and the illness is a basis of the claim or a defense

Privacy should extend to include group therapy, conjoint therapy, marital therapy, and family therapy. In such cases, the permission of all parties should be required for release of information. An exception to the automatic waiver for civil litigation should be made for domestic relations cases including divorce, separation, and custody. If the mental status of a party is relevant to the disposition in such a case, then independent evaluation should be required if the party did not wish to authorize release by a treating physician or therapist.

Privacy in communications dealing with criminal matters should be absolute. This is a drastically different recommendation from both H.R. 3444 and H.R. 2979. It is a crucial one.

If a privacy bill incorporated these principles, I am sure that psychiatrists and other physicians would enthusiastically endorse such a bill. Unfortunately the current bills are cause only for fear, trepidation, and concern both for our liberties and for restricted access to reasonable medical care.

Yours truly,



Irwin N. Perr, M.D., J.D.
 Professor of Psychiatry and
 Director of Forensic Psychiatry,
 Rutgers Medical School
 Adjunct Professor of Law, Rutgers
 Law School-Newark
 President, American Academy of
 Psychiatry and the Law

INP/jmf



COLLEGE OF MEDICINE AND DENTISTRY OF NEW JERSEY

RUTGERS MEDICAL SCHOOL

University Heights

Piscataway, New Jersey 08854

Institute of Mental Health Sciences

Department of Psychiatry
(201) 463-4439

Community Mental Health Center
November 5, 1979

Richardson Preyer, Chairman
Government Information and Individual
Rights Subcommittee
Committee on Government Operations
Rayburn House Office Building, Room B-349-B-C
Washington, DC 20515

Dear Mr. Preyer:

I am writing to follow up my letter of July 10, 1979 in which I reviewed two proposed bills, H.R. 3444 and H.R. 2979. I had been contacted because of my position as President of the American Academy of Psychiatry and the Law; I responded with a rather detailed analysis of the bills because of my own interest and the extreme importance of such bills which significantly affect doctor-patient relationships and professional practice.

Subsequently this matter was discussed by the members of the Executive Committee of the American Academy of Psychiatry and the Law which met on October 25, 1979. The Committee endorsed the opinions offered in my letter of July 10th and authorized me to continue to represent the Academy in further communications dealing with privacy bills.

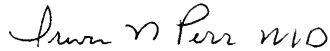
The Academy, of course, is generally in favor of bills that would protect the privacy of patients and doctor-patient communications. We are keenly aware of the need for protection and are concerned about possible abuses or exceptions that would negate or adversely affect the stated intent of the acts.

The Academy would appreciate the opportunity to be kept informed about proposed or evolving changes in the bills and to be able to respond constructively to such proposals. As an organization devoted to the study of the interaction of medicine, psychiatry, and the law and to the reasonable application of our professional knowledge for sociolegal purposes, we have a most important

Richardson Preyer, Chairman
Page 2

interest in any actions taken by Congress. I would therefore wish to be listed as representative of the Academy for any purposes that might be deemed helpful or appropriate by your committee.

Yours truly,

A handwritten signature in cursive script, appearing to read "Irwin N. Perr M.D.", written in dark ink.

Irwin N. Perr, M.D., J.D.
Professor of Psychiatry
Immediate Past President, AAPL

INP/jmf

cc: Nathan T. Sidley, M.D.
President, AAPL

N. LETTER FROM JOHN H. ROMANI, Ph. D., PRESIDENT, AMERICAN
PUBLIC HEALTH ASSOCIATION



AMERICAN PUBLIC HEALTH ASSOCIATION

1015 Eighteenth Street, N.W., Washington, D.C. 20036 • (202) 467-5000

JOHN H. ROMANI, Ph.D., *President*

July 13, 1979

JUL 18 1979

The Honorable Richardson Preyer
Chairman, Government Information &
Individual Rights Subcommittee of
the Committee on Gov. Operations
Rayburn House Office Bldg.
Room B-349-B-C
Washington, D. C. 20515

Dear Mr. Preyer:

The American Public Health Association appreciates the opportunity to review and to comment on the two bills relating to the confidentiality of medical records (HR 2979 and HR 3444). We support the concept of protection of the privacy of individuals and the confidentiality of their medical records. At the same time, we feel strongly that the valuable information contained in medical records must be accessible for public health, epidemiological and biomedical research. To make such research more effective and efficient, access should not be unduly hampered by unnecessary and tortuous rules, regulations, paperwork and delays. The rights of citizens to absolute privacy must be balanced against the need to pursue research into health hazards for the ultimate goal of the prevention of disease. Such balancing of rights is ever present in epidemiological studies. At present, the need for research is most acute with regard to the hazards of ionizing radiation, toxic substances, and other environmental pollutants, and to the end-points of cancer, cardiovascular diseases, and congenital malformations.

The proposed legislation is helpful in correcting many of the difficulties encountered in public health research which derive from earlier legislation. In addressing the problems of medical records in HR 2979 and HR 3444, as separate from the combined total of all records (including tax, census, criminal, administrative records, and so forth), we feel that both bills take a significant step forward.

In reviewing HR 2979, several questions arise which suggest that some clarification is needed:

1. In order to conduct epidemiological and public health research, medical records are needed from a variety of sources. While the

need for access to hospital records is obvious, much needed information is often contained in records maintained by private physicians. Many physicians provide services under Medicaid and Part B, Medicare and thus they may be included under HR 2979. Much depends upon the interpretation of the word "entity" under Title I, Section 101 (9)(B). This assumption may, however, not be correct and therefore we feel should be clarified.

2. In Section 101 (3) of the bill, does "person" have the legal connotation of a natural person or an institution, or the colloquial connotation of a natural person?
3. Section 101 (8)(B) defines an "appropriate" institutional review board, and the bill indicates several possibilities as being "appropriate." In practice, epidemiologic projects must clear a number of institutional review boards. For example, (a) if a federal agency supports the research, and (b) if the contractor is a private, non-profit health corporation and (c) if the study is a collaborative study based on records from 15 hospitals, then a minimum of 17 institutional review boards would be involved. It would greatly facilitate the conduct of such studies if a stream-lining mechanism could be devised. To date, we have seen no attempts at such stream-lining in any proposed legislation.
4. The use of the word "individual" in HR 2979 is not always clear. On page 3, line 20, it appears to refer to the patient. On page 12, line 21, could the word "individual" be misinterpreted to mean an employee? The top of page 13 (2) suggests that it could be.

It appears that records relating to psychiatric care, drug abuse, and alcoholism would be less available for public health and epidemiological research than other records. These are important public health problems and we fear that any additional restraints to research in the prevention of such public health problems would be detrimental to progress in tackling them.

Both HR 2979 and HR 3444 focus on medical care facilities, and specify the conditions under which they may release medical records without specific authorization. It is not completely clear how this inter-relates with proscriptions to access by federal agencies and federally-supported contractors or grantees. Would HR 2979 override such restrictions? This is an important consideration in public health research because much is federally supported. We would suggest that the bill be specifically worded to allow for such an over-ride.

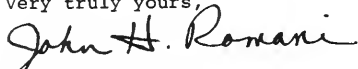
We strongly support the provisions pertaining to criminal penalties for obtaining medical records through false pretenses (HR 2979, Section 152 and HR 3444, Section 301). On balance, it is far better to use such penalties on the relatively few individuals guilty of transgressions than to impede public health research which has the potential of benefit to thousands of individuals. But, again, this must all be balanced with the judicious protection of the privacy of the subject.

In general, we found HR 2979 easier to understand than HR 3444. Double negatives such as those in HR 3444, Section 105, for example, are difficult to follow. On the other hand, HR 3444 addresses certain specific issues as records in penal and correctional institutions which are not included in HR 2979. It is becoming increasingly evident that covering all eventualities with regard to records will ultimately require a large body of law. What may be needed is their simplification to expedite public health research.

Neither bill addresses the need for protection of research data from subpoena. Currently information which may have been gathered for public health research under rigorous standards to protect the confidentiality of individuals may be subject to subpoena. We urge that language be added to address this important issue.

Again, we appreciate the opportunity to present our views. Members of the Association with expertise in this issue are available for further elaboration of the points raised in our comments. Please contact the Association if we can be of further assistance.

Very truly yours,

A handwritten signature in cursive script that reads "John H. Romani". The signature is written in dark ink and is positioned above the typed name and title.

John H. Romani, PhD
President

O. LETTER FROM EDWARD A. MORTIMER, JR., M.D., CASE WESTERN
RESERVE UNIVERSITY

CASE WESTERN RESERVE UNIVERSITY • CLEVELAND, OHIO 44106



July 20, 1979

Re: H.R. 2979

The Honorable Richardson Preyer, Chairman
Subcommittee on Governmental Information
and Individual Rights
Room B-349-C, Rayburn House Office Building
Washington, D.C. 20515

Dear Mr. Preyer:

I am writing to express maximum support for H.R. 2979, a bill that you have introduced related to the privacy of medical records. I also have one comment.

I am a physician-epidemiologist actively engaged in research and teaching in the area of epidemiology. Some of this research has been and currently is supported by federal grants from the National Institutes of Health. All of this research has been reviewed and endorsed without reservation by appropriate institutional review boards concerned with the rights and safety of patients, as well as by the National Institutes of Health. I believe that I am recognized in the field of epidemiology as a capable individual of integrity who acts in a responsible fashion in relation to confidential medical information.

My major reason for supporting H.R. 2979 strongly is that a great deal of epidemiologic research, including at least two federally funded projects in which I have been engaged in recent years, is significantly compromised by the current restrictions on access to medical information related to individuals. Two brief examples of the kinds of difficulties in which members of my department and I find ourselves in doing this type of legitimate research may be of interest.

A group of women medical students here developed an idea and a proposal to the NIH for the study of the epidemiology of cancer of the ovary. NIH thought it was an excellent idea, funded it a couple of weeks ago, and it is being conducted under my sponsorship. In this study women with cancer of the ovary are being interviewed, a blood specimen is obtained and their pathological specimens obtained at the time of surgery at various hospitals in the area are being reviewed by us. To do this they give us signed informed consent. Because a few of these women may not know their exact diagnosis, we neither wish nor are permitted to use the term "cancer" in the consent form or verbally. But to access the pathological specimens, to which each study patient agrees, we need to know the patient's record number from the Regional Cancer Registry which was originally established under federal funding. The lawyers for the Cancer Registry, operated by the Greater Cleveland Hospital Association, have given the opinion

School of Medicine
2119 Abington Road
Telephone 216-368-3713

Edward A. Mortimer, Jr. M.D.
Elsabeth Severance Prentiss Professor
of Community Health and Pediatrics
Chairman, Department of Community Health

that the Hospital Association is subject to liability if the data on the Registry is released to us without informed, written consent by the patient. With the exception of the hospital number, the patient has already given us the information in the Registry (and far more besides) or has given us permission to get the same information in reviewing the pathological specimens. The lawyers felt that we should add to the consent form the patient's permission to acquire the cancer data abstract from the Cancer Data System, putting us in a Catch 22 situation for the simple reason that that addition then announces to the patient that she has cancer. Ultimately this will probably be straightened out by putting some weasel words into the patient consent form, saying something about a "case abstract" without mentioning cancer. But the process of trying to solve this is costing a great deal of time and a lot of money.

The second example is a study being conducted by a well-trained and respected epidemiologist in my department. The study has two purposes, which are to examine the effectiveness of an emergency medical services program in this area (paid for in part by federal funds) and to examine certain epidemiologic characteristics surrounding automobile crash injuries, including the relationship of those injuries to the types of vehicles involved. To conduct this study, approximately 35,000 emergency room records in 42 hospitals in Northeastern Ohio must be examined. All this is done with appropriate human research review. The same hospital lawyers as above maintain that our examining these records and computerizing them anonymously nonetheless placed the hospitals and the Hospital Association in a position of liability, and only after interminable negotiations was the study initiated. The lawyers now state that they made a mistake and that they never should have permitted examination of these records without permission from each of the 35,000 individuals involved.

Thus, certain kinds of epidemiologic research in the health area, such as the examples cited above, are becoming increasingly difficult to conduct. Such research is important for the public good, and I believe that H.R. 2979 represents an optimum means by which it will be possible to respond to the public's need to know, while at the same time protecting the rights of the individual.

I do have one comment in terms of a suggested modification of the bill. Epidemiologic research often entails long-term follow-up of patients, some of whom may be difficult to trace. Accordingly, it is not infrequently desirable to try to find patients by other means, such as school board records and the like. Current concerns about privacy have extended beyond the medical field, and epidemiologic research is also hampered by this. A specific example follows.

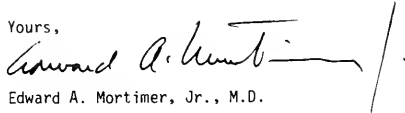
In the early 1960s all poliomyelitis vaccines were contaminated with a monkey virus, called SV-40, which produces malignant tumors in hamsters. This contamination was not recognized for some time. It therefore became important to follow up human beings who received these inadvertently contaminated vaccines to determine whether the virus had any such untoward effects in man. One study of adults has indicated no such effect. The only other definitive study that I

know of is one that I have recently completed in relation to children who in the newborn period received these vaccines. To find nearly 1100 children who were born in the early 60s, in 1978, is no easy task and this was further complicated by the fears of school boards and other agencies in relation to giving out patient's addresses. The Social Security Administration refused to help, and letters from the National Cancer Institute expressing the legitimacy of this study which it funded were to no avail.

The point of this example is that there may be other sources than the medical record that would be of considerable utility in finding patients lost to follow-up for legitimate epidemiologic reasons.

I know that the problem of privacy is a matter of maximum concern to many others conducting epidemiologic research. I also know that members of the American Epidemiological Society, to which I belong, would be pleased to supply additional examples and support, if desired, including testimony at your discretion. Please feel free to contact me.

Yours,



Edward A. Mortimer, Jr., M.D.

EAM:cwg

cc: Dean Frederick C. Robbins

Dr. Theodore C. Eickhoff
Secretary-Treasurer
American Epidemiological Society

Dr. Paul Bonner
Greater Cleveland Hospital Association

P. LETTER FROM JOHN RECKLESS, M.D., F.A.C.P., THE JOHN RECKLESS CLINIC

THE JOHN RECKLESS CLINIC
PROFESSIONAL ASSOCIATION

CROSSDAILE OFFICE PARK
1816 FRONT STREET- SUITE 310
DURHAM, NORTH CAROLINA 27705
919-383-1502

JOHN RECKLESS, M.D. F.A.C.P.
MEDICAL DIRECTOR

July 24, 1979

Congressman Richardson Preyer
2344 Rayburn House Office Building
Washington, D. C. 20515

Dear Congressman Preyer:

I am increasingly troubled by the amounts of information that insurance companies are requesting in connection with evaluation of patients' claims affecting their psychiatric visits to me and other colleagues. It is becoming increasingly apparent now that the middle class who are in the field for loans, insurances, mortgages, etc., are experiencing leakages of information from medical records which are read by an investigative company, and these leaks are being transmitted and the information used adversely against them in other areas.

These are the very people in the salary range of \$12,000 - \$24,000 who cannot afford private medical care except when reimbursed by insurance premiums that they have already paid.

A composite situation which could describe a number of situations I am now dealing with involves a person who, in addition to having a manic depressive illness which requires Lithium, has a medical condition which requires the use of antihypertensives. Because of the possible negative interactional nature of these two drugs, the patient must come in frequently for drug regulation. This frequency of visits which require careful blood monitoring of the patient's Lithium level (Lithium is a drug which is important and specific in the treatment of manic depressive illness) is viewed by the third party payer as possibly excessive. The patient probably is being seen twice a week over a period of months. Psychotherapy is being utilized in addition to the drug, Lithium.

The insurance company then requests the complete initial interview with mental status together with all progress notes. The progress note would be viewed as that note which the doctor makes at each session which, in addition to the blood interactional level of the two drugs, also includes details of the patient's life situation since psychotherapy is being utilized in addition to pharmacotherapy. The patient,

being a health care provider, refuses to release this information on the grounds that once it is released to the insurance company, the information that is contained in the progress notes would then be accessible to any of the various computer-based medical exchange programs such as the Medical Information Bureau. As you know, this is an organization that retains the medical files on a large percentage of American patients which can then be used as a pool of information from which other insurance companies can withdraw information. If the patient instructs me not to release the progress notes, the insurance company refuses to pay for the treatment on the grounds that the doctor does not supply the information.

In the meantime the patient, without the benefit of the third-party reimbursement, may be unable to pay for his psychiatric visits (if he is in the \$12,000 - \$24,000 salary range) and may be forced to discontinue treatment--or if he is a wealthier patient, pays it anyway--or if he is a poor patient, is forced to drop out of treatment.

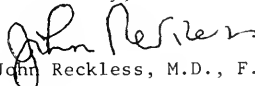
My view is that since the progress notes of the psychiatrist are necessarily more detailed in terms of the patient's life situation involving work, family interactions, marital interactions, financial transactions, and possibly some escapades of a variety of sorts, these notes should not be requested. Instead a medical report containing the reasons for the patient's initial visit, the reasons for the continuation of the visits, the diagnosis, treatment outline, and expected prognosis should be sufficient to satisfy the insurance company's need for information.

In the event of controversy, I would suggest an independent review by a psychiatrist who sees the patient face-to-face with the patient being shown that review and having the opportunity either to countersign it indicating that he has read it and agrees to forward it to the insurance company or (if he does not agree with the report) to withdraw the claim or seek sanction through due legal process.

I hope that the point is made that I see continuing hardship on almost a daily basis concerning patients who are being asked for information which I, as a psychiatrist and as a person who has worked as a medical advisor for H.E.W. for over sixteen years, know is not necessary to make an adjudication of the validity of the claim.

I can only believe that the insurance companies have an interest in bringing pressure to bear for patients not to submit themselves to this type of faceless invasion of their very personal and intimate life histories, problems, and events.

Yours truly,


John Reckless, M.D., F.A.C.P.

NOTE WITH REGARD TO THE MEDICAL INFORMATION BUREAU: In certain states, the insurance department requires that you be given a copy of this notice. Read it carefully.

Information you provide will be treated as confidential except that the Beneficial National Life Insurance Company may, however, make a brief report thereon to the Medical Information Bureau, a non-profit membership organization of life insurance companies, which operates an information exchange in behalf of its members. Upon request by another member insurance company to which you have applied for life or health insurance coverage to which a claim is submitted, the MIB will supply such company with the information it may have in its files.

Upon receipt of a request from you, the Bureau will arrange disclosure of any information it may have in your file. (Medical information will be disclosed only to your attending physician.) If you question the accuracy of information in the Bureau's file, you may contact the Bureau and seek a correction in accordance with the procedures set forth in the Federal Fair Credit Reporting Act. The address of the Bureau's information office is Post Office Box 105, Essex Station, Boston, Massachusetts 02112, telephone number (617) 426-3660. Beneficial National Life Insurance Company may also release information in its file to other life insurance companies to whom you may apply for life or health insurance, or to whom a claim for benefits may be submitted.

Q. LETTER FROM PAUL L. THOMPSON, NATIONAL COMMANDER,
DISABLED AMERICAN VETERANS



SEP 7 1979



Motto: "If I cannot speak good of my comrade, I will not speak ill of him."

DISABLED AMERICAN VETERANS

NATIONAL SERVICE and LEGISLATIVE HEADQUARTERS
807 MAINE AVENUE, S.W.
WASHINGTON, D.C. 20024
(202) 554-3501

September 5, 1979

Honorable Richardson Preyer
House Government Operations Committee
U. S. House of Representatives
Washington, DC 20515

Dear Congressman Preyer:

This letter is in reference to H. R. 2979, the Federal Privacy Medical Records Act of 1979, which is presently receiving serious consideration by the Subcommittee on Government Information and Individual Rights of the House Committee on Government Operations.

Addressing the fact that our federal government is playing an ever increasing role in the provision, payment and regulation of medical services to the American people, the above cited legislation seeks to prevent the misuse and/or abuse of medical information which may occur through indiscriminate governmental disclosure--both within and between various federal Departments and Agencies. This would be achieved (by the bill) through addition to, and reinforcement of, current law in the areas of patient consent for release of medical information and individual access to and correction of medical records.

In accordance with certain fundamental rights recently given statutory expression through the Freedom of Information and Privacy Acts of 1974, the Disabled American Veterans recognizes the need for this legislation and, indeed, we have no quarrel with its fundamental intent.

However, in terms of its application to the Veterans Administration, we very definitely perceive a major, albeit unintentional, adverse impact upon the adjudication of VA benefit claims in which judgement determinations require information relative to the existence and extent of physical/mental disabilities and causes of death.

As you might imagine, the medical evidence pertinent to the adjudication of most VA claims emanates from care received in governmental facilities--mainly VA and military.

Inherent to the timely and appropriate consideration of these claims is the capacity for a free and unencumbered flow of information between VA medical facilities (under the Department of Medicine and Surgery) and VA adjudication personnel (under the Department of Veterans Benefits). In addition to this intra-Agency activity, the VA claims process also requires intergovernmental exchanges of information with such entities as the Social Security Administration and the Department of Defense.

Such working relationships within the VA and between the VA and other federal Departments and Agencies presently do exist. Under the terms of H. R. 2979, they would be greatly altered to the detriment of the VA claims process and, we believe, to the detriment of VA claimants themselves.

With the exception of a few, narrowly drawn exemptions, the bill states that VA intra and intergovernmental (medical) information disclosures could only be permissible after obtaining patient consent. Thus, the current routine and expeditious exchange of information between the VA's Department of Medicine and Surgery and Department of Veterans Benefits-- absolutely necessary for benefit entitlement determinations-- would be grossly interrupted. Similar exchanges between the VA and other governmental agencies would also be impaired.

Furthermore, as the bill requires "specificity" of the information to be disclosed (by the consenting claimant), the likelihood of incomplete or nonrelevant medical information transmissions must be considered probable. At best, this would require follow-up information requests and lead to further delays in the adjudication process. At worst, it would result in the denial of benefits to which a claimant is statutorily entitled.

Programs most affected would be: service-connected disability compensation, nonservice-connected pension, service-connected and nonservice-connected death benefits, vocational rehabilitation, specially adapted housing and automobile programs, as well as other types of VA benefits and services which require the examination and evaluation of medical evidence.

We also view with alarm the effects that H. R. 2979 would have upon the present access to VA records held by the accredited representatives of the various veterans' organizations.

For example, DAV National Service Officers who have been assigned "power of attorney" by VA claimants presently have complete access to VA and military service records. This is absolutely necessary if our organization is to provide the best possible representation, assuring receipt of all benefits to which there is statutory entitlement. Many times this entails a complete and comprehensive examination of VA/military service records. As I understand H. R. 2979, such examinations could not be authorized due to the specificity requirement associated with the patient consent provisions.

I also foresee that "patient consent" would create many problems involving the proper representation of claimants who have been adjudged by the Veterans Administration to be incompetent.

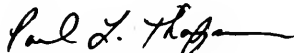
Finally, under the terms of the bill, the Department of Health, Education and Welfare would be given the responsibility of formulating regulations following enactment into law. We do not believe that HEW should have regulatory authority over any aspect of VA operations, especially those that involve the adjudication of claims and delivery of VA benefits and services.

For the above reasons, the DAV strongly opposes H. R. 2979 as presently written. In terms of the basic intent of the bill and its present application to the Veterans Administration, we believe the adverse impacts upon the VA's adjudication process (and beneficiaries of that process) would far outnumber the individual protections gained in the areas of patient confidentiality and access to medical records.

We respectfully recommend to the Government Operations Committee that H. R. 2979 be amended to exempt the Veterans Administration from being affected by its provisions. Failing that, at the very least, we urge the Committee to "broaden" the intra/intergovernmental disclosure and patient consent provisions so as not to impede and disrupt the VA benefit claims process.

Members of my Washington staff would be most pleased to meet with you or members of your staff in further discussion of this important subject. Thank you very much for your kind attention to this letter.

Sincerely yours,



PAUL L. THOMPSON
National Commander

PLT:lrd

**R. LETTER FROM PERRY L. TAYLOR, D.D.S., PRESIDENT, DELTA
DENTAL PLANS ASSOCIATION**



SEP 17 1979

Delta Dental Plans Association

211 East Chicago Avenue
Chicago, Illinois 60611
Phone (312) 337-4707

September 11, 1979

Congressman Richardson Preyer, Chairman
House Committee on Governmental Affairs
Subcommittee on Government Information
and Individual Rights
B349 C Rayburn House Office Building
Washington, D.C. 20515

Dear Congressman Preyer,

I am writing about the medical records privacy legislation currently pending before your committee.

It is our understanding that the legislation, as drafted, would not affect the individual practitioner. It is our thought, however, that a statement outlining what Delta Dental Plans Association is, and how we function with regard to dental records might be helpful to the committee in its deliberations.

Delta Dental Plans Association is an Illinois nonprofit corporation which includes in its membership 43 nonprofit dental service corporations ("Plans") organized in 42 states and the District of Columbia. The members of Delta Dental Plans Association currently provide prepaid dental care coverage to approximately 14 million individuals, through contracts with employers, joint labor and employer trust funds and governmental entities. Although practices and the requirements of state law vary somewhat from state to state, typically these Plans function by means of contractual arrangements with dentists by which dentists agree to provide services to subscribers pursuant to certain terms and conditions. One of these conditions may be that the dentist agrees that the fees charged to the dental service corporation and its subscriber shall not exceed the dentist's "usual fee". The "usual fee" is defined as the fee which the dentist regularly or normally charges under similar circumstances.

The usual fee provisions of the agreements between Delta Plans and their participating dentists are similar to requirements enacted by Congress in the Medicare law that charges by physicians reimbursed by Medicare shall be reasonable "and not higher than the charge applicable, for a comparable service and under comparable circumstances, to the policy holders and subscribers of the carrier" which administers benefits on behalf of the Secretary of Health, Education and Welfare (42 U.S.C. § 1395 L.C. (b) (3)). These

"With Delta . . . Everybody Benefits"

requirements, both in the Medicare law and as followed by Delta Plans, reflect a concern that the existence of a third party insurer or payor, whether governmental or private, should not justify the charging of a higher fee for professional services than would otherwise be charged.

In general the concept that charges should be "usual" regardless of the presence of insurance or prepayment is accepted and supported by the dental profession, and most dentists voluntarily comply with this concept. However, a number of Plans audit a select number of dental offices, usually on a random basis, to monitor compliance with agreements to charge "usual" fees and to detect instances of fraud or abuse with respect to charges which exist among a small minority of dentists. It should be noted that, in order to audit fees charged by the dentist to the Plan to determine whether they are "usual", it is necessary to examine not only records of services provided to subscribers of the Plan, but also records relating to billings made by the dentist to patients who are not subscribers to the Plan or covered by other insurance. This must be done to determine whether the dentist's charges to the Plan are "usual" in comparison with the charges to others. This necessitates some inquiry into a dentist's billing records relating to individuals who have no connection with a Plan. However, the scope of this inquiry is very limited and does not involve any invasion of privacy of these individuals. The Plan is not interested in the nature of their health problems, the services provided to them or any other personal information. It merely needs to ascertain the amount of fees charged. Sometimes it is possible to do this without even seeing the identity of the patients who receive the bills, but this is not always possible. That would depend upon the character and method of organization of the dentist's billing records.

The purpose of this background information is to point out that the type of audit of health records which is described is an important and necessary activity to avoid undue inflation in health care costs as a result of government and privately funded health insurance and prepaid health care programs. If properly conducted, this type of audit causes little, if any, intrusion into the privacy of individual patients,

since it is not concerned with health history, the nature of health problems, or the type of service received, except to the extent that the verification of a fee charged must be related to a service for which the fee applies. We are concerned, however, that privacy legislation, possibly by the use of broad general language with respect to the non-disclosure of health records, should not later be construed to prohibit this type of legitimate audit activity.

Please feel free to make this statement a part of the official record. If you have any questions, or if we can provide any additional information, please do not hesitate to contact us.

Sincerely,

 , DDS
Perry L. Taylor, D.D.S.
President

cc: Government Programs Committee
Mr. Peter Sloss
Mr. Kenneth Williamson
Mr. Joseph Rees

S. LETTER FROM DONALD H. SCHWAB, DIRECTOR, VETERANS OF
FOREIGN WARS OF THE UNITED STATES



VETERANS OF FOREIGN WARS OF THE UNITED STATES

NATIONAL LEGISLATIVE SERVICE

Office of Director

STATEMENT OF

DONALD H. SCHWAB, DIRECTOR
NATIONAL LEGISLATIVE SERVICE
VETERANS OF FOREIGN WARS OF THE UNITED STATES

TO THE

SUBCOMMITTEE ON GOVERNMENT INFORMATION AND INDIVIDUAL RIGHTS
COMMITTEE ON GOVERNMENT OPERATIONS
U. S. HOUSE OF REPRESENTATIVES

WITH RESPECT TO THE "FEDERAL PRIVACY OF MEDICAL RECORDS ACT"

WASHINGTON, D. C.

SEPTEMBER 17, 1979

MR. CHAIRMAN AND MEMBERS OF THE SUBCOMMITTEE:

Thank you for the privilege of presenting to this distinguished Subcommittee the views of the Veterans of Foreign Wars of the United States with respect to pending legislation.

My name is Donald H. Schwab and it is my privilege to serve the 1.85 million men and women of the Veterans of Foreign Wars as their National Legislative Director.

The legislation under consideration, H.R. 2979, to protect the privacy of medical records maintained by medical care facilities was introduced by the Honorable Richardson Preyer and referred jointly to the Committees on Government Operations, Interstate and Foreign Commerce, and Ways and Means.

Although we of the Veterans of Foreign Wars of the United States believe as the instant legislation states that, "the right to privacy is a personal and



fundamental right protected by the Constitution of the United States," we also firmly believe the stringent restrictions laid down by H.R. 2979 would be a disservice to those it seeks to protect in that it would successfully thwart the ability of the Veterans Administration and accredited service officers of veterans' organizations from pursuing the claims of veterans which could well have far reaching untoward ramifications on the financial security of the veteran, his dependents, and survivors and, yes, even the future treatment of the veteran in other facilities even under emergent conditions.

As a result of the pending legislation, the 80th National Convention of the Veterans of Foreign Wars of the United States held in New Orleans, Louisiana, August 17-24, 1979, passed Resolution No. 772 which is herein quoted in toto:

"PRIVACY OF MEDICAL INFORMATION

"WHEREAS, legislation has been introduced in the Congress of the United States to protect the privacy of medical records maintained by medical care facilities, identified as H.R. 2979, the 'Federal Privacy of Medical Records Act;' and

"WHEREAS, this legislation would prevent the Department of Veterans Benefits of the Veterans Administration from obtaining admission and medical treatment information from VA medical care facilities without the written consent of the claimant; and

"WHEREAS, the Department of Veterans Benefits ability to obtain a veterans service medical records from the Department of Defense would be impaired without the prior written consent of the veteran; and

"WHEREAS, the written consent required under the pending legislation must specify the information to be disclosed; and

"WHEREAS, the substitution consent provision for incompetency does not recognize the VA incompetency rating and would require that incompetency be judicially determined; and

"WHEREAS, the Secretary of Health, Education and Welfare would write the regulations implementing the bill after enactment, and such regulations would directly affect VA operations; and

"Whereas, restricting the VA from medical records of veterans would greatly impair the ability of accredited Service Officers of the V.F.W. and other veterans organizations in their pursuit of claims, even though they hold a properly executed Power of Attorney; and

"WHEREAS, there may be other restrictive nuances in the bill or amendments thereto; now, therefore

"BE IT RESOLVED, by the 80th National Convention of the Veterans of Foreign Wars of the United States, that we oppose passage of H.R. 2979, or similar legislation, unless the VA is specifically exempted from its provisions to assure the freeflow of information between the Department of Veterans Benefits and VA medical care facilities and the Department of Veterans Benefits and the Department of Defense."

In view of the foregoing, and as stipulated in the resolved clause of our resolution, the Veterans of Foreign Wars requests this legislation be not advanced unless the Veterans Administration is specifically exempted from its provisions.

Thank you.

T. LETTER FROM JOHN F. HEILMAN, NATIONAL LEGISLATIVE
DIRECTOR, DISABLED AMERICAN VETERANS

STATEMENT OF
JOHN F. HEILMAN
NATIONAL LEGISLATIVE DIRECTOR
DISABLED AMERICAN VETERANS
TO THE
SUBCOMMITTEE ON GOVERNMENT INFORMATION & INDIVIDUAL RIGHTS
OF THE
HOUSE GOVERNMENT OPERATIONS COMMITTEE
SEPTEMBER 17, 1979

MR. CHAIRMAN AND MEMBERS OF THE SUBCOMMITTEE:

On behalf of the 619,000 members of the Disabled American Veterans, may I say that we appreciate this opportunity to present our views on H. R. 2979, the Federal Privacy of Medical Records Act of 1979.

Mr. Chairman, it is the exception, rather than the rule, for the DAV to appear before this distinguished Subcommittee in matters relating to veterans' federal benefits and services--the Veterans Affairs Committees of the House and Senate, of course, having sole purview over the vast majority of legislation affecting the interests of America's veteran population, their dependents and survivors.

However, this is not the case in the instance of the pending bill.

Addressing the fact that our federal government is playing an ever increasing role in the provision, payment and regulation of medical services to the American people, H. R. 2979 seeks to prevent the misuse and/or abuse of medical information which may occur through indiscriminate governmental disclosures--both within and between various federal departments and agencies. This would be achieved through addition to, and reinforcement of, current law in the areas of patient consent for release of medical information and individual access to, and correction of, medical records.

In accordance with certain fundamental rights recently given statutory expression through the Freedom of Information and Privacy Acts of 1974, the Disabled American Veterans recognizes the need for this legislation and, indeed, we have no quarrel with its fundamental intent.

However, in terms of its application to the Veterans Administration, we very definitely perceive a major, albeit unintentional, adverse impact upon the adjudication of VA benefit claims in which judgment determinations require information relative to the existence and extent of physical/mental disabilities and causes of death.

As you might imagine, the medical evidence pertinent to the adjudication of most VA claims emanates from care received in governmental facilities--mainly VA and military.

Inherent to the timely and appropriate consideration of these claims is the capacity for a free and unencumbered flow of information between VA medical facilities (under the Department of Medicine and Surgery) and VA adjudication personnel (under the Department of Veterans Benefits). In addition to this intra-agency activity, the VA claims process also requires intergovernmental exchanges of information with such entities as the Social Security Administration and the Department of Defense.

Such working relationships within the VA and between the VA and other federal departments and agencies presently do exist. Under the

terms of H. R. 2979, they would be greatly altered to the detriment of the VA claims process and, we believe, to the detriment of VA claimants themselves.

With the exception of a few, narrowly drawn exemptions, the bill states that VA intra and intergovernmental (medical) information disclosures could only be permissible after obtaining patient consent. Thus, the current routine and expeditious exchange of information between the VA's Department of Medicine and Surgery and Department of Veterans Benefits--absolutely necessary for benefit entitlement determinations--would be grossly interrupted. Similar exchanges between the VA and other governmental agencies would also be impaired.

Furthermore, as the bill requires "specificity" of the information to be disclosed by the consenting claimant, the likelihood of incomplete or nonrelevant medical information transmissions must be considered probable. At best, this would require follow-up information requests and lead to further delays in the adjudication process. At worst, due to adjudication decisions based on an incomplete record, it could result in the denial of benefits to which a claimant may be statutorily entitled.

Programs most affected would be: service-connected disability compensation, nonservice-connected pension, service-connected and non-service-connected death benefits, vocational rehabilitation, specially adapted housing and automobile programs, as well as other types of VA benefits and services which require the examination and evaluation of medical evidence.

We also view with alarm the effects that H. R. 2979 would have upon the present access to VA records held by the accredited representative of the various veterans' organizations.

For example, DAV National Service Officers who have been assigned "power of attorney" by VA claimants presently have complete access to VA and military service records. This is absolutely necessary if our organization is to provide the best possible representation, assuring receipt of all benefits to which there is statutory entitlement. Many times this entails a complete and comprehensive examination of VA/military service records. As I understand H. R. 2979, such examinations could not be authorized due to the specificity requirement associated with the patient consent provisions.

I also foresee that "patient consent" would create many problems involving the proper representation of claimants who have been judged by the Veterans Administration to be "incompetent."

It is my understanding that members of the Subcommittee staff have had several discussions with officials of the Veterans Administration, wherein the VA voiced concerns regarding the bill's effect upon their benefit adjudication process.

It is also my understanding that the Subcommittee's staff indicated (to the VA) that, rather than placing a specific exemption in the bill, the VA's concerns would be dealt with in the form of "legislative history language." I believe the Subcommittee staff also offered the opinion that VA Form 21-526 (Application for Compensation or Pension) was sufficient "patient consent" to allow for intra-VA and other governmental disclosure.

The DAV does not believe that these approaches offer practical or desirable solutions.

First of all, there are a myriad of VA benefit application forms in addition to a "21-526" which cover the vast array of VA benefits and services. Also, under current VA law, regulation and policy, it is possible for a veteran, or an accredited representative acting on behalf of a veteran, to file an "informal claim" for a benefit--such informal claim not being made through completion of a benefit application form. Could these situations be covered through a "legislative history language" approach?

Also, certain benefits can be obtained by a veteran without his taking any application action--either formal or informal. For example, if a veteran remains hospitalized in a VA facility in excess of 21 days due to a service-related disability, his monthly VA disability compensation payments, if less than total, are automatically increased to the 100% rate. They remain at this rate so long as the inpatient status is continued and revert back to the "normal" rate upon the hospital discharge of the veteran.

These hospital admission and discharge notifications are automatically sent to VA Department of Veterans Benefits personnel by the medical facility involved. Interruption and/or delay of such notices would result in VA benefit overpayments and/or underpayments--much to the distress of the veteran. Could "legislative intent language" adequately deal in these areas?

It is our considered opinion that, if the VA adjudication process is to be fully and completely protected from disruption through the employment of a "legislative history" approach, then such an approach, of necessity, would have to be extremely thorough and explicit--so much so that it would, in essence, allow the VA to "run completely through" the bill (as if it were granted a complete exemption).

We also ask if the Subcommittee has thought in terms of the number of additional VA personnel that would be required if the VA is to comply with the governmental disclosure provisions of H. R. 2979. Are you prepared to support such a staffing increase and so inform your Budget Committee?

Finally, under the terms of the bill, the Department of Health, Education and Welfare would be given the responsibility of formulating regulations following enactment into law. We do not believe that HEW should have regulatory authority over any aspect of VA operations--especially those that involve the adjudication of claims and delivery of benefits and services.

For the above reasons, the DAV strongly opposes H. R. 2979 as presently written. In terms of the basic intent of the bill and its present application to the Veterans Administration, we believe the adverse impacts upon the VA's adjudication process (and beneficiaries of that process) would far outnumber the individual protections gained in the areas of patient confidentiality and access to medical records.

We respectfully recommend to the Government Operations Committee that H. R. 2979 be amended to exempt the Veterans Administration from

being affected by its provisions. We believe that such an outright exemption is the only approach that can fully address the concerns that we have presented here today.

In closing, may I again say that the DAV deeply appreciates being given the opportunity to present our views on this important subject.

U. LETTER FROM FAYE WATTLETON, PRESIDENT, PLANNED PARENTHOOD-WORLD POPULATION, HEADQUARTERS OF PLANNED PARENTHOOD FEDERATION OF AMERICA, INC.



Planned Parenthood-World Population HEADQUARTERS OF PLANNED PARENTHOOD FEDERATION OF AMERICA, INC.

Washington Office SUITE 305, 1220 19th STREET, N.W., WASHINGTON, D.C. 20036/(202) 296-4012

A MEMBER OF THE INTERNATIONAL PLANNED PARENTHOOD FEDERATION

September 24, 1979

SEP 26 1979

The Honorable Richardson Preyer, Chairman
House Committee on Government Operations
Subcommittee on Government Information
and Individual Rights
Room B-349C
Rayburn Building
Washington, DC

Jeannie I. Rosoff
Director, Washington Office

Dear Mr. Chairman and Members of the Subcommittee:

Founded by
Margaret Sanger
1879-1966

CHAIRPERSON
Frederick C. Smith

TREASURER
William H. Gilbert

SECRETARY
AND ASSISTANT TREASURER
Nancy Young Duncan

EXECUTIVE COMMITTEE
Andrew F. Greensfelder

Chairperson
Marjorie Andreen
Joan G. Babbott, M.D.
Allen G. Barnes, M.D.
Berdette T. Campbell
Rollin M. Dick
Martha Stott Dianer
Nancy Young Duncan
Henry W. Foster, Jr., M.D.
Ronald J. Gewirtz
William H. Gilbert
Ollan B. Hinnant
Diana Kinzie
Ann Dancy Norman
Walter A. Ruch, Jr., M.D.
Felice M. Schwartz
Frederick C. Smith
Richard Soderstrom, M.D.
Benjamin R. Sturges

PRESIDENT
Faye Wattleton

I am writing on behalf of the Planned Parenthood Federation of America with reference to various pieces of legislation before the Committee (H.R. 2979, H.R. 2465 and H.R. 3444) concerning confidentiality of medical records, and request that this letter be entered into the hearing record. Our concern with respect to these proposals centers on the provisions for the release of minors' health care records. Through 186 affiliates in 43 states and the District of Columbia, Planned Parenthood provides education and medically supervised voluntary family planning services to 1.2 million women a year, including 445,000 teenagers. Accordingly, we are well aware of the complexity of deciding when minors are sufficiently mature to make responsible, independent decisions about their health care and the release of their medical records.

Most young people can benefit from the advice and support of their parents in making important decisions and Planned Parenthood's policy and clinical practice encourages parental involvement. Nevertheless, we recognize that a substantial number of our adolescent clients would be deterred from seeking services they need and want if their confidentiality were to be breached in any way. In virtually all cases these young people would incur significantly increased risks of unwanted pregnancy--with all its adverse consequences for themselves, for their families and for society--if they did not receive contraceptive care. Accordingly, Planned Parenthood does not condition the provision of services on parental involvement and it routinely holds its young clients who have consented to their own care solely responsible for the release of their medical records. This policy is consistent with a series of U.S. Supreme Court decisions which affirm the privacy rights of minors in reproductive health care matters.

Planned Parenthood Federation of America, Inc. National Office· 810 Seventh Avenue, New York, N.Y. 10019

PURPOSE

to provide leadership

- in making effective means of voluntary fertility regulation, including contraception, abortion, sterilization, and infertility services, available and fully accessible to all as a central element of reproductive health care;
- in achieving, through informed individual choice, a U.S. population of stable size in an optimum environment;
- in stimulating and sponsoring relevant biomedical, socio-economic, and demographic research;
- in developing appropriate information, education and training programs, and to support and assist efforts to achieve similar goals in the United States and throughout the world

BOARD OF DIRECTORS

Marjorie Andreen
 Joan G. Babbott, M.D.
 Allan C. Barnes, M.D.
 H. J. Barnum, Jr., M.D.
 Robert E. Bason
 Marilyn Broad
 Cameron Brown
 Donald S. Buzard
 Berdelle T. Campbell
 Dorothy Carpenter
 Rollin M. Dick
 Martha Stott Diener
 Robin Chandler Duke
 Nancy Young Duncan
 Henry W. Foster, Jr., M.D.
 Tommy B. Fox
 Beverly W. Gabrio, Ph.D.
 Ronald I. Gevurtz
 William H. Gilbert
 Andrew F. Greensfelder
 Dee Gronbeck
 John A. Harris
 Jean Hennessey

Ollen B. Hinnant
 Jean L. Hoffman
 Frances D. Hooks
 John A. Hooper
 Elizabeth H. Howell
 Ms. Tommie C. Jones
 Eugene Katz
 Betsy Kearney
 Theodore M. King, M.D.
 Diana Kinzie
 Helene Koch
 Barbara W. Lee
 Raphael B. Levine, Ph.D.
 Kate Rand Lloyd
 Katherine Maddox
 Fred Mallender, II
 Gerard Martin
 Karen J. Matsuda
 Nan Tucker McEvoy
 Lenora McIntyre
 Thomas Mendenhall, II, Ph.D.
 Edward P. Morgan
 Stewart R. Mott

Ernst D. Mueller
 Jerome K. Nagel
 Ann Duecy Norman
 Deborah Oakley, Ph.D.
 Norma E. Porres, M.D.
 Russell H. Richardson
 Walter A. Ruch, Jr., M.D.
 Felice N. Schwartz
 Horace L. Sheffield
 Drew C. Simonson
 Frederick C. Smith
 Richard Soderstrom, M.D.
 Merrie Spaeth
 Herbert M. Stein
 Rabbi Richard S. Sternberger
 Benjamin R. Sturges
 Joan DeManty Webber
 Charles F. Westoff, Ph.D.
 Nancy N. White
 Eloise Culmer Whitten
 Nanette R. Winter
 Robert G. Zimbelman, Ph.D.

BOARD OF ADVISORS

Isaac Asimov, Ph.D.
 Cass Canfield
 Mrs. Ernest N. Calhoun
 Mrs. Walter E. Campbell
 Pierre S. Dupont, IV
 Mrs. James Faulkner

Mrs. Robert M. Ferguson
 Mrs. Alan F. Guttmacher
 Louis M. Hellman, M.D.
 Jerome H. Holland, Ph.D.
 Mrs. Albert D. Lasker
 George N. Lindsay, Esq.

Mrs. Francis T. P. Plimpton
 Eugene Power
 Donald B. Straus
 Mrs. Henry C. Taylor
 Abigail Van Buren
 Mrs. Fifield Workum


Adele D. Hoffmann, M.D., of the American Academy of Pediatrics has presented testimony before this Committee with a carefully balanced developmental approach to weighing the rights and interests of minors against the desirability of involving parents in the health care of their children. The key guidelines presented by the Academy provide that:

- "Parents should have authority for consent to release of all medical records for children less than age 12,"
- "Parental and minors' consent both should be required for record release for patients between 12 and 14," and
- "All minors 15 and older and those under this age who have given sole consent to health services and/or have conveyed confidential information documented in the record should consent unilaterally to the release of their record."
- "Persons under the age of majority (as determined by the jurisdiction within which the provisions of this act are being exercised) and eligible to exercise rights conjointly or independently may elect to waive these rights and assign them to parents, guardian or legal representatives or, in the absence of such an individual, to another adult of the minor's choice (N.B.: to cover instances of minors not living at home or otherwise functioning in an independent manner where they may wish to have an adult act for them, but not the parent.)"

We endorse the American Academy of Pediatrics' statement and strongly urge the Committee to adopt its recommendations.

If we can be of further assistance, please feel free to call on us.

Very truly yours,


Faye Wattleton
President

dvw

References:

1. A survey published in Family Planning Perspectives, Vol. 10, No. 5, September/October, 1978, attempted to ascertain the effect of a mandatory parental notification requirement on teenage attendance at family planning clinics. It found that 55 percent of teenagers attending clinics did so with their parents' knowledge. An additional nine percent would continue to come to clinics if their parents were informed and four percent would stop being sexually active. However, 32 percent would discontinue clinic attendance and would have intercourse using less effective non-medical methods of contraception or no method. (Copy of article enclosed).
2. Planned Parenthood of Central Missouri v. Danforth, 428 U.S. 52 (1976), Carey v. Population Services International 431 U.S. 678 (1977), and Baird v. Bellotti, 47 U.S.L.W. 4969 (U.S. July 2, 1979) (No. 78-329).

Does Your Mother Know...?

By Aida Torres

During the 1970s, laws and policies which had restricted teenagers' opportunity to obtain medical contraceptive services have been removed or relaxed.¹ Many courts have upheld the right of competent young people to consent for their own contraceptive care, even if they are minors. Thus, in 1976, the U.S. Supreme Court upheld a Utah district court ruling that federally funded family planning programs violate federal law if they require parental consent as a condition of providing contraception to minors.² During the same year, in cases testing abortion consent laws from Missouri and Massachusetts, the Court declared that it was an unconstitutional violation of a minor's privacy for a state to require parental permission to obtain an abortion.³ The following year, in a decision that invalidated a New York statute that had prohibited the distribution of nonprescription contraceptives to minors under 16, the Court made clear that the principles set forth in the Missouri case applied to contraception as well as abortion.⁴ During the same year, however, a district court judge in Michigan ruled that a state-funded family planning clinic could not distribute contraceptives to minors without first notifying their parents.⁵ That ruling has not been enforced pending results of an appeal to the Court of Appeals. No other state has a law requiring notification of parents before contraceptives may be provided to minors, although Florida, Louisiana, Maryland and Montana require notification of parents of unwed minors who obtain abortions.⁶ An amendment to Title X of the Public Health Service Act, introduced earlier this year in the U.S. Senate, would have

Many teenagers inform their parents when they come to a family planning clinic. Most of those who do not, however, would stop coming to the clinic if their parents were told of their attendance, and a substantial proportion would have sex without using any birth control method.

required all U.S. family planning clinics funded under the act to notify parents before giving contraceptives to minors.⁷ The bill never reached the Senate floor, but it is possible that a similar amendment may be offered when the Title X bill comes up for debate in the House.

Those who seek parental notification requirements apparently believe that most teenagers who receive contraceptive services from clinics do so without telling their parents. They argue that such exclusion of the parents from the decision to obtain contraception weakens family ties and erodes parental authority, and that because the parents do not know what birth control drugs their children may be taking, they cannot properly exercise their parental responsibility for the health care of their children. Some, of course, oppose contraception on moral grounds and seek simply to reduce the number of teenagers receiving birth control services.

As laws and policies were liberalized through the mid-1970s, the number of teenagers who obtained contraceptives from family planning clinics grew by two-thirds from an estimated 690,000 in 1972 to nearly 1.2 million in 1976. The number of teenage clinic patients under age 18 (the age that defines majority in almost all states) increased even more—by about nine-tenths—from 231,000 in 1972 to nearly 440,000 by 1976.⁸ Unwed teenagers' use of contraception, a very substantial proportion of which is obtained from family planning clinics, is

credited with having averted 680,000 premarital adolescent pregnancies in 1976.⁹ If parental notification laws were enacted, what proportion of teenage patients would stop coming to clinics and abandon the use of effective contraception while remaining sexually active? What proportion of teenage patients already inform their parents that they are getting contraceptives at family planning clinics? To get answers to these questions, a pilot study was conducted of unmarried teenagers under age 18 who obtain contraceptives from organized family planning programs.

Methods and Sample Characteristics

The study was based on responses to a self-administered survey questionnaire that asked each respondent what her age was, with whom she lived, whether or not her parents knew she attended a family planning clinic, and what she would do if her parents had to be notified that she was receiving contraceptives at the clinic. The survey sought to determine whether the respondent would continue sexual activity and use medical contraceptive methods obtained at the clinic, use drugstore or other nonmedical methods obtained outside the clinic, use no method, or stop sexual activity.

⁸Unpublished distribution from DHEW's National Reporting System for Family Planning Services applied to the numbers of patients estimated in AGI, Data and Analyses for 1977, Revision of DHEW Five-Year Plan for Family Planning Services, New York, 1977.

Aida Torres is Senior Research Associate with The Alan Guttmacher Institute.

The questionnaire was distributed to all young women who attended 53 clinics in Arizona, California, Illinois, Missouri, New York, Pennsylvania, South Carolina, Tennessee, Texas and Washington during a two-week period in April and May 1978. Clinics included in the survey were not randomly selected. In soliciting participation from the clinics, however, considerable effort was taken to obtain a reasonable geographic distribution and representation of the various types of agencies, and to include clinics which serve large numbers of teenagers. The clinics that participated in the survey represented nine hospitals, 17 health departments, 13 Planned Parenthood affiliates and 14 other agencies, such as community action centers and neighborhood health clinics.

Eighty-two percent of the young women who received questionnaires filled them out, yielding a total of 2,215 usable responses—2,054 from patients under 20 years of age and 161 from older women. In this study, only data for 1,442 unmarried adolescents aged 17 and younger (94 percent of 1,535 respondents in this age group) are considered. There were relatively large numbers of patients from southern and midwestern states, and relatively small numbers from the western and northeastern states. The results, therefore, cannot be considered representative of patients under 18 in all U.S. family planning clinics.

Of the 1,442 unmarried minors in the total sample, 41 percent were 17 years of age; 32 percent were aged 16; 17 percent were 15 years of age; 10 percent were 14 and younger. Eighty-seven percent lived with their parents; seven percent lived with relatives; and six percent lived alone or with other persons (e.g., boyfriends or roommates).

Findings

As may be seen from Table 1, 55 percent of the young patients said their parents knew that they attended a family planning clinic; 45 percent reported that their parents were not aware. Teenagers under 15 were least likely to attend a clinic without their parents' knowledge, but the proportions reporting parental awareness were high among the other age groups as well, in no instance falling below 50 percent.

The 55 percent of teenagers who said that their parents knew that they came to the family planning clinic, as well as an additional nine percent (for a total of 64



Many teens said they would stop using birth control if the clinic notified their parents.

percent), reported that they would continue using contraceptive services provided at the clinic if parental notification were required. Twenty percent would discontinue clinic attendance, but would use nonmedical methods of contraception; 12 percent would go on having sex, but use no method. Only four percent said that parental notification would cause them to stop having sex.

The proportion of teenagers who would discontinue attendance at the clinic but use nonmedical methods varied with age: About one-fourth of the 17-year-olds said they would rely on some form of nonclinic contraception, compared with fewer than one-sixth of girls under 15 years of age. There were no notable differences between age groups in the proportions who would continue sexual activity but use no method, or in the percentages who would stop having sex.

There were very large differences from locality to locality in the proportions of patients who said that their parents knew they were getting contraceptives at the clinic, and there were smaller but still substantial differences according to the type of agency the respondent attended. There were surprisingly few such differences, however, in the responses of those whose parents did not know of their clinic attendance: Overall, about two in 10 would attend the clinic; some four in 10 would use nonclinic contraception; three in 10 would have

sex but use no method; and one in 10 would stop having sex.

Discussion

The finding that more than half of the teenagers in this pilot study reported that their parents knew they were getting contraception at a family planning clinic challenges one of the principal premises underlying the efforts to secure parental

Table 1. Percentage distribution of teenage patients' responses to the following question regarding their attendance at a family planning clinic: If your parents had to be notified that you were receiving medical contraceptives (pill, IUD, diaphragm) in the clinic, would you have come? If not, what would you do?

Response	Age				
	Total	<15	15	16	17
Parents know, would come	55	65	59	58	50
Parents don't know, would come	9	5	8	8	11
Parents don't know, would not come					
Have sex but use nonmedical method	20	14	18	19	24
Have sex but no contraception	12	13	11	11	12
Not have sex	4	3	5	4	3
Don't know	*	0	1	0	*
N	1,442	147	244	463	588

*Less than 0.5 percent



notification laws, namely, that minors will not inform their parents about their sexual activity and contraceptive behavior unless forced to do so. It is notable that the younger the teenagers receiving services, the higher the proportion of parents who are aware of their clinic attendance. While the extent of parental awareness differs greatly from area to area and agency to agency, it is clear that a substantial proportion of teenagers do not shut their parents out of this important aspect of their lives.

On the other hand, this study also suggests that many teenagers, for various reasons, feel that they cannot confide in their parents about their sexual and contraceptive behavior. The data indicate that requiring parental notification will not have the presumably desired effect of discouraging sexual activity among these teenagers, or even of increasing substantially the proportion who would willingly tell their parents about their clinic attendance. Rather, the requirement of parental notification would apparently cause a substantial number of young people who are now protected against unwanted pregnancies to drop out of the clinic, and to use no contraception or less effective drugstore or folk methods. A recent study found that just 5.8 percent of teenagers who used medical methods consistently ever got pregnant, compared to 58.0 percent of those who used no method and 23.9 percent of those who were inconsistent us-

ers.⁹ It seems clear, therefore, that parental notification laws would be redundant for the large numbers of young people who confide in their parents about their contraceptive behavior, and would result in a substantial increase in unwanted pregnancies—which would end mostly in illegitimate births and abortions—among the considerable numbers of teenagers who are unable to talk to their parents about this aspect of their lives.

References

1. E.W. Paul, H.F. Pilpel and N.F. Wechsler, "Pregnancy, Teenagers and the Law, 1976," *Family Planning Perspectives*, 8:16, 1976, and E.W. Paul, "Danforth and Bellotti: A Breakthrough for Adolescents," *Family Planning/Population Reporter*, 6:3, 1977.
2. *Jones v. T.H.*, 425 Fed. Supp. 873 (D. Utah 1975), affirmed in part 425 U.S. 986 (1976).
3. *Planned Parenthood of Central Missouri v. Danforth*, 428 U.S. 52 (1976); and *Bellotti v. Baird*, 428 U.S. 132 (1976).
4. *Carry v. Population Services International*, 431 U.S. 678 (1977).
5. *Doe v. Irwin*, 428 Fed. Supp. 1198 (W.D. Mich. 1977), 559 F. 2d 1219 (6th Cir. 1977); Second District Court opinion, Nov. 23, 1977.
6. P. Donovan, The Alan Guttmacher Institute (ACI), personal communication, Aug. 1978.
7. S. 2614.
8. M. Zelnik and J.F. Kantner, "Contraceptive Patterns and Premarital Pregnancy Among Women Aged 15-19 in 1976," *Family Planning Perspectives*, 10:135, 1978.
9. Ibid.

Start with AVC... comprehensive, economical therapy to combat vaginitis due to major vaginal pathogens* and to provide prompt onset of symptomatic relief...with the prescribing flexibility of two dosage forms.

AVC™

Cream/Suppositories
AVAILABLE ONLY ON PRESCRIPTION
Brief Summary

***INDICATIONS:** Based on a review of AVC by the National Academy of Sciences—National Research Council and/or other information, FDA has classified the indications as follows:
 "Probably effective: For the relief of symptoms of vulvovaginitis where isolation of the specific organism responsible (usually *Trichomonas vaginalis*, *Candida albicans*, or *Hemophilus vaginalis*) is not possible.
 NOTE: When the offending organism is known, treatment with a specific agent known to be active against that microorganism is preferred.
 "Possibly effective: For the treatment of trichomoniasis, vulvovaginal candidiasis, and vaginitis due to *Hemophilus vaginalis* or other susceptible bacteria.
 Final classification of the less-than-effective indications requires further investigation.

CONTRAINDICATIONS: AVC should not be used in patients known to be sensitive to the sulfonamides.

PRECAUTIONS: As with all sulfonamides, the usual precautions apply. Patients should be observed for manifestations such as skin rash or other evidence of systemic toxicity, and if these develop, the medication should be discontinued.

ADVERSE REACTIONS: Although some absorption of sulfanilamide may occur through the vaginal mucosa, systemic manifestations attributable to this drug are infrequent. Local sensitivity reactions such as increased discomfort or a burning sensation have occasionally been reported following the use of topical sulfonamides. Treatment should be discontinued if either local or systemic manifestations of sulfonamide toxicity or sensitivity occur.

DOSAGE AND ADMINISTRATION: 1 suppository (about 6 g) or 1 suppository intravaginally once or twice daily. Improvements in symptoms should occur within a few days, but treatment should be continued through one complete menstrual cycle unless a definite diagnosis is made and specific therapy initiated. If there is no response within a few days or if symptoms recur, AVC should be discontinued and another attempt made by appropriate laboratory methods to isolate the organism responsible (*Trichomonas vaginalis*, *Candida albicans*, *Hemophilus vaginalis*) and institute specific therapy. Douching with a suitable solution before insertion may be recommended for hygienic purposes. A pad may be used to prevent staining of clothing.

Product information as of November, 1974.

AVC Suppositories are manufactured by R. P. Scherer Corporation, 9425 Grinnell Avenue, Detroit, Michigan 48213.

MERRELL NATIONAL LABORATORIES
Division of Richardson-Merrell Inc.
Cincinnati, Ohio 45215 U.S.A.

Merrell

6-3875 (1/7/74)

V. LETTER FROM R. OTTO MELETZKE, ASSISTANT GENERAL COUNSEL,
AMERICAN COUNCIL OF LIFE INSURANCE, AND DAVID J. PATTISON,
ASSISTANT WASHINGTON COUNSEL, HEALTH INSURANCE ASSOCIA-
TION OF AMERICA

American Council of Life Insurance
HEALTH INSURANCE ASSOCIATION OF AMERICA

1850 K Street, N.W.,
Washington, D.C. 20006
(202) 862-4000

1750 K Street, N.W.
Washington, D.C. 20006
(202) 331-1336

October 18, 1979

Honorable Richardson Preyer
Chairman, Governmental and Individual
Rights Subcommittee
Committee on Government Operations
U.S. House of Representatives
Washington, D.C. 20515

Dear Mr. Preyer:

This is in response to your invitation to the American Council of Life Insurance and the Health Insurance Association of America several months ago to submit a statement for the record with respect to legislation on medical records confidentiality currently pending in your Subcommittee.

The delay in our response stems from two considerations. First, our two associations have been following closely the hearings held by your Subcommittee on this important subject, and second, we have been awaiting the release of the Administration's proposed "Fair Insurance Information Practices Act" which, of course, contains several important proposals designed to protect the confidentiality of medical records.

Since your Subcommittee has not yet arrived at a final decision as to what form the medical records confidentiality proposal will take when reported to the full committee, we are hopeful that the technical comments which appear below will be helpful to you and your staff as this important legislation moves forward.

At the outset, one important point should be made. Any legislation dealing with medical records confidentiality which is finally approved by your Subcommittee should, to the extent possible, be consistent with the Administration's proposed "Fair Insurance Information Practices Act", particularly in the area of specifying the form of authorizations by individuals for the disclosure of medical information. In this regard, we are certain that you appreciate the need for certain medical information by life and health insurance companies, with proper authorization, for both underwriting and claims purposes. And, if such access, with appropriate authorization, is impeded, risk classification and claims administration will be unduly restricted to the detriment of insurance applicants and policyholders alike.

Our technical comments on H.R. 3444 and H.R. 2979 appear below.

H.R. 3444--Title I.

Section 101(b). While it may be the intent of this provision, as it refers to "an appropriate person" (as defined in the regulations of the Secretary) to focus principally on licensed physicians, we would urge that serious consideration be given to including the term "licensed physician" in addition to "an appropriate person (as defined in regulations of the Secretary)". Insofar as much medical information is sensitive and can, in certain circumstances, be susceptible of misinterpretation by individuals, we believe that licensed physicians should certainly be the principal professionals which medical facilities should allow to inspect medical information and furthermore, to determine any potential harm to individuals.

Section 104. One problem that occurs to us in this section is that by providing that a medical care facility may disclose medical information only to "properly identified persons", and by placing discretion as to the extent of the disclosure in the facility, there exists the possibility that the facility could inadvertently hamper both the issuance of insurance policies and the prompt payment of claims. This is because the facility may not be in a position to know which medical information is relevant for an insurer's purpose. Here it seems to us that medical information as provided in an appropriate authorization should be disclosed without discretion. We would therefore suggest that the phrase "as provided in the authorization" be inserted after "properly identified persons", and further, that all of the provision following the parenthetical clause be stricken.

Section 105(d). We are most concerned with the last sentence in Section 105(d) which, as drafted, provides that an authorization may be revoked in whole or in part at any time. Life and health insurers when requesting medical information with proper authorization will rely on the authorization as they proceed to underwrite a case or process a claim. Thus, any revocation obviously disrupts this process, most often to the detriment of the applicant or the insured. While obviously individuals should be able to exercise a revocation of an authorization, we would suggest that some provision be added to subsection (d) which recognizes unique situations involving life and health insurance. Thus, we would suggest language along the following lines: "An authorization may be revoked in whole or in part at any time, except where an authorization is executed in connection with an application for a life or health insurance policy, in which case the authorization shall expire two years from the issue date of the insurance policy, and when signed in connection with a claim for benefits under any insurance policy, the authorization should be valid during pendency of such claim. Finally, any revocation shall be transmitted in writing."

Section 108. In this section we would suggest a technical change by striking the word "solely" in the title to the Section as well as in the Section itself. The reason here is that medical information that a facility maintains more often than not will not be compiled "solely" for civil litigation.

Title III

Sections 305 and 310(3). Section 305 would vest the Secretary of HEW with authority to prescribe regulations to carry out the provisions of the proposed Act. In this respect, we would suggest that either in such regulations or in a specific definition in the bill that the term "individual" be defined to include situations where the individual is incapacitated or deceased, thus recognizing next of kin or legal representatives. Otherwise, the beneficiary of a life or health insurance policy could be precluded from authorizing the release of medical information, a result that certainly would not be in the public interest. In addition, in Section 310(3) we would urge that the term "health care provider" should be redefined in clause (B) to read as follows: "Any person or other entity that provides health, diagnostic and treatment services to individuals,".

H.R. 2979

Section 114(3). Our comment on this provision is similar to that expressed in connection with Section 104 of H.R. 3444, above; that is, that a properly executed authorization should permit disclosure of medical records. Perhaps this result is intended by the provision, but this should be made clear either in the legislation or any accompanying legislative history.

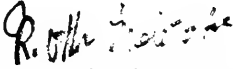
Section 115(a)(4). In this provision, we would suggest that the term "a request for" be inserted before "the disclosure", for purposes of clarification as to the duration of the authorization.

Section 115(b). As indicated above in our comments on H.R. 3444 with respect to Section 105(d), we are most concerned with revocations or amendments of authorizations, and would suggest the same language be added as indicated above.

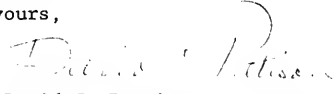
Section 152. In this section we would suggest that the words "willfully and knowingly" be added after "false or fraudulent pretenses or". We do not believe persons should be subjected to criminal penalties under this section who did not know or should not reasonably be expected to have known they were in possession of a false or fraudulent certification.

We very much appreciate the opportunity to make these comments, and if we can be of any assistance to you or to your staff with respect to these comments, please do not hesitate to call upon us.

Sincerely yours,



R. Otto Meletzke
Assistant General Counsel
American Council of Life
Insurance



David J. Pattison
Assistant Washington Counsel
Health Insurance Association
of America

W. LETTER FROM WILLIAM M. HERMELIN, ADMINISTRATOR,
AMERICAN HEALTH CARE ASSOCIATION



American Health Care Association 1200 15th Street, Washington, DC 20005 (202) 833-2050

November 9, 1979

Honorable Richardson Preyer
Chairman, Subcommittee on Government
Information & Individual Rights
United States House of Representatives
Washington, D.C. 20515

Dear Mr. Preyer:

The American Health Care Association, which represents some 7,500 long term care facilities across the United States, would like to submit for the record the attached testimony on legislation affecting the privacy of medical records, currently before the Subcommittee on Government Information & Individual Rights.

Sincerely,

A handwritten signature in dark ink, appearing to read "William M. Hermelin", is written over the typed name.

William M. Hermelin
Administrator
Government Services Department

WMH:munm

Enc.

STATEMENT OF THE
AMERICAN HEALTH CARE ASSOCIATION
PRESENTED BEFORE
THE SUBCOMMITTEE ON
GOVERNMENT INFORMATION AND INDIVIDUAL RIGHTS
UNITED STATES HOUSE OF REPRESENTATIVES

November, 1979

Mr. Chairman and Members of the Subcommittee:

The American Health Care Association (AHCA), the nation's largest trade association of licensed providers of long term health care, is pleased to submit comments on legislation establishing Federal policies on the privacy of medical records.

Our comments, which are broad in nature, address several concepts contained in a number of pieces of legislation that have been introduced on this issue. We do not intend to critique each one of the bills, but rather suggest some basic principles, which if adopted, would create a viable medical records policy for long term care facilities.

AHCA recognizes the need to protect a patient's medical record from misuse. Medical records are, of course, subject to legitimate access by many individuals within and outside the health care institution which maintains them. There are also individuals who, while not "users", have a special interest in a particular patient's records. In developing a practical and rational policy for the protection of these records, it is essential that the interests of these various individuals be considered.

These interests include: users of medical record information. (such as researchers, planners, and reimbursement sources); governmental representatives; individuals, such as family members, from whom information is received; and, most important the patient. Balancing these conflicting interests is a most difficult task.

From the provider's perspective, a principal objective should be a medical records policy which permits development of the least cumbersome system for achieving its objectives. Compliance is more certainly and easily assured in a simple system. In addition, a simple system will be less costly for both providers and the agency responsible for enforcement.

A second major consideration stems from the fact that many long term care providers often are placed in the difficult situation of acting as intermediaries between physicians and the residents of facilities or their families. Since the need for direct physician contact with many residents in nursing homes is intermittent because of the stable condition of the residents, it is often difficult for the provider to involve the attending physician in routine, administrative decisions affecting the resident. We are concerned that this would apply to access to medical records. Moreover, long term care providers may be drawn into disputes between the families of residents and the attending physician over the appropriateness of treatment prescribed by the physician. AHCA would urge that the ultimate medical records procedures endorsed by the Congress should not exacerbate this problem.

Among the specific problem areas which providers could encounter are the following:

1. In many long term care institutions there are large numbers of patients who have not been adjudicated incompetent but who

are chronically disoriented. Permitting them access to their own records, or allowing them to permit outsiders access to their records could create serious problems. The latter situation can be particularly burdensome when family members are financially responsible for the patient's care. In this situation some mechanism for permitting delay so as to obtain joint permission from both the patient and a responsible family member should be considered.

2. The opportunity of a patient to "contest the accuracy" (as used in S.503) of his medical record is preferable to giving him the right to "correct" his record. Because much of what appears in a medical record reflects the observations and opinions of the recorder, it would be impossible for the patient to "correct" entries in his record.
3. The burden of conformance and reporting should be placed upon the user of information (except for the patient and his family and/or legal guardian) rather than the provider of services. While some record of those who obtain access should be made part of the patient's record, the agency or organization that regularly acquires access to patient records should record and report its total activity to the ultimate enforcement agency, and should be responsible for showing conformance with the law. The service provider cannot possibly "police" the activities of all users of medical records.
4. The Congress should carefully delineate the parameters within which the Secretary of HEW will develop regulations. Precise definitions of the categories of medical record information users, their rights and responsibilities, and a clear limitation on the complexity and frequency of reporting requirements should

be included in the legislation. The cost of alternatives for enforcement should be a major factor in implementation.

5. Government agencies should not be permitted unlimited access to or use of records, but should be subject to reasonable limitations and be subject to reporting requirements. The law should provide protection from governmental, as well as private, intrusions on the privacy rights of the individual patient.
6. Persons who obtain information legitimately, but willfully and knowingly misuse or do not adequately safeguard it, as well as those who obtain information illegally, should be subject to sanctions. This would protect the patient and establish the principle that the provider cannot police activities of all those who obtain information from him.

X. LETTER FROM BOYD THOMPSON, EXECUTIVE VICE PRESIDENT, AMERICAN PROFESSIONAL STANDARDS REVIEW ORGANIZATIONS

American Association

AMERICAN ASSOCIATION OF PROFESSIONAL STANDARDS REVIEW ORGANIZATIONS

11325 SEVEN LOCKS ROAD SUITE 214 POTOMAC, MARYLAND 20854 301/983-0404

OFFICERS

President
Harry S. Wells, M.D.
Charleston, West Virginia

Vice President
George P. Lucht, M.D.
Cleveland, Ohio

Secretary
James Byrne, M.D.
Miami, Florida

Treasurer
James Pilrod, M.D.
Laconia, New Hampshire

Past President
John Busman, M.D.
Portland, Oregon

DIRECTORS

Anthony Altieri, M.D.
New York, New York

Robert Becker, M.D.
Joliet, Illinois

Andrew J. Casanovi, M.D.
Hartford, Connecticut

Joseph Denko, M.D.
Scranton, Pennsylvania

Robert F. Ithier, M.D.
Seattle, Washington

Neil Kennedy, M.D.
Albuquerque, New Mexico

J. Louis Schrickel, M.D.
Salt Lake City, Utah

Howard Stroncutler, M.D.
Lumberton, North Carolina

John M. Wasserman, M.D.
Torrance, California

Douglas Westhoff, M.D.
Jefferson City, Missouri

Philip Walker, II, Ex Officio
Columbia, South Carolina

Speaker of the House
Karnegie Plaza, M.D.
Denver, Colorado

Vice Speaker of the House
Donald Brown, M.D.
Irwin, Pennsylvania

December 5, 1979

Mr. Richardson Preyer
Congress of the United States
House of Representatives
Washington, D.C. 20515

Dear Mr. Preyer:

Thank you for your invitation to comment on the provisions of your bill, H.R. 5935, the "Federal Privacy of Medical Information Act".

The combination of sections 101 (particularly the definition of the term audit), 102 (particularly subsection (b)(1)), and 125 would have the result that Professional Standards Review Organizations would continue to have access to medical information necessary to perform the functions the Social Security law requires of them.

As you know, Professional Standards Review Organizations themselves are limited by Federal statute in the information which they can disclose. In fact, the recent court decision which would make individual data held by PSROs subject to disclosure under the Freedom of Information Act has produced great qualms among those of us who work with this program and explains our strong current efforts to seek a legislative solution to the problem.

Since your bill maintains the original intent of the PSRO legislation (by retaining the PSRO disclosure provision in section 1166 of the Social Security Act) we support your bill without qualification.

Again, we very much appreciate this opportunity to express our views on this bill.

Sincerely,


Boyd Thompson
Executive Vice President

BT/ms

Y. LETTER FROM MARCHIA KRAFT GOIN, M.D., CHAIRPERSON, COMMITTEE ON CONFIDENTIALITY, AMERICAN PSYCHIATRIC ASSOCIATION



American Psychiatric Association

1700 Eighteenth Street, N.W., Washington, D.C. 20009 • Telephone: (202) 797-4900

Board of Trustees, 1979-1980

Alan A. Stone, M.D.
President
Donald G. Langsley, M.D.
President-Elect
Lewis L. Robbins, M.D.
Vice-President
Peter A. Martin, M.D.
Vice-President
H. Keith H. Brodie, M.D.
Secretary
Charles B. Wilkinson, M.D.
Treasurer
Robert W. Gibson, M.D.
Jack Weinberg, M.D.
Jules H. Masserman, M.D.
Lee B. Macht, M.D.
John Talbott, M.D.
Abram M. Hostetter, M.D.
William B. Spriegel, M.D.
Henry B. Brackin, Jr., M.D.
Robert A. Moore, M.D.
David Starrett, M.D.
Mary Ann Bartusis, M.D.
Gene Usdin, M.D.
Rita R. Rogers, M.D.
Robert O. Pasnau, M.D.
Assembly, 1979-1980
Robert O. Pasnau, M.D.
Speaker
Melvin M. Lipsett, M.D.
Speaker-Elect
Jack B. Kremens, M.D.
Recorder

John C. Nemah, M.D., *Editor*
American Journal of Psychiatry
Melvin Sabshin, M.D.
Medical Director
Jay B. Cutler, J.D.
Special Counsel and
Director of Government Relations
Donald W. Hammersley, M.D.
Deputy Medical Director
Carolyn B. Robinowitz, M.D.
Deputy Medical Director
Robert L. Robinson, M.A.
Director, Public Affairs
Jeanne Spurlock, M.D.
Deputy Medical Director
Henry H. Work, M.D.
Deputy Medical Director
Jack W. White, D.B.A., *Deputy*
Director, Business Administration

December 10, 1979

The Honorable
Richardson Preyer
Chairman
House Government Operations
Subcommittee on Government Information
and Individual Rights
U.S. House of Representatives
Washington, D.C. 20515

Dear Mr. Chairman:

The Committee on Confidentiality of the American Psychiatric Association, a medical specialty society representing over 25,000 psychiatrists nationwide, has reviewed H.R. 5935 and appreciates the opportunity to present our comments to your Committee. This bill, more than its predecessors, moves toward the intent of protecting the public's right to privacy respecting medical information. However, there are several provisions where we would recommend modification to insure the fullest protection of medical record confidentiality.

For the reasons hereinafter stated with respect to the provisions cited and in order to achieve the necessary protection of confidential psychiatric information, we would recommend that the bill be amended minimally as follows:

- 1) On page 50, at the end thereof, insert the following:

Title IV-Special Limitations on Disclosures Confidentiality of Records

Sec. 401. Records of the identity, diagnosis/prognosis or treatment of any patient which are maintained in connection with the performance of any government authority funded

program or activity relating to mental health treatment or related services shall restrict disclosure or use of medical information relating to psychiatric, psychological, or mental health examination, care or treatment in accordance and conformity with section 333 of the Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment and Rehabilitation Act of 1970, and section 408 of the Drug Abuse Office and Treatment Act of 1972.

- 2) On page 9, between lines 14 and 15, insert the following:

Provided, however, that such medical information will not include medical information relating to psychiatric, psychological or mental health examination, care or treatment with respect to personal notes regarding a patient wherein there is recorded:

- (i) sensitive information disclosed in confidence by other persons on the condition that such information would never be disclosed to the patient or other persons;
- (ii) sensitive information disclosed by the patient that would be injurious to the patient's relationships to other persons; and
- (iii) the speculation, impressions, suspicions or any feelings about something that is not based upon known facts.

Regarding specific provisions of H.R. 5935, we urge the Committee to consider the following:

Section 123. This section allows hospitals to release

information which may have a benign and insignificant effect on the patient in a non-psychiatric facility but which could prove damaging for those in psychiatric facilities. We suggest amending this section to read: "When the patient is in a psychiatric care facility, the staff should exercise discretion, ordinarily disclosing this information only to someone in the immediate family, next of kin or legal representative of the patient, or to individuals with whom the patient has a personal relationship." Informing the general public that a person is a patient in a psychiatric care facility can, unfortunately, prove to be damaging to a patient in his work and other relationships.

Section 124. Needed health research should not be impeded because of difficulty in locating patients in order that they authorize disclosures of information. However, except in instances where a public hazard necessitates the immediate initiation of a project, authorization for the release of information would be appropriate. We suggest amending this section to read that "Except in the instances of a public health hazard, where time is of the essence, authorization by the patient for release of information should be required unless reasonable attempts to locate the patient prove fruitless."

Section 125. Certain basic information is necessary for the purposes of audit and utilization review. However, medical records in a psychiatric facility may contain a great deal of personal information, not necessary for an audit or utilization review. Their automatic release would be an unnecessary breach of privacy. We suggest this section be amended to the effect that in a psychiatric facility, access should be limited to substantive clinical material and not include the physician's or hospital staff's notes which report the patient's personal thoughts and feelings that have been revealed to these people in confidence.

Section 130. Psychiatric treatment differs from other forms of medical treatment. The psychiatric physician must encourage and facilitate the development of trust, enabling patients to reveal their troublesome thoughts, feelings and behaviors. The need for trust and the information revealed makes it somewhat analogous to the confessor/penitent relationship. To use information obtained in this way for law enforcement purposes is as invasive of someone's rights as using information obtained in the confessional. It is also similar to obtaining a confession without first informing someone of his Miranda rights or compelling him to testify against himself in a court of law. It is obvious that if psychiatric patients were told, "I must inform you that whatever you say may be used against you in a court of law..." that many in need of psychiatric treatment, and whose treatment has the potential of benefitting the public, would not seek to obtain it. The authors of this bill have wisely realized this need for the protection of medical records when patients are being treated for alcoholism and drug abuse. It may not be as easy for someone unfamiliar with the nature of psychiatric treatment to realize that the same protection is needed for all patients. We recommend that Section 130 be amended to read: "A medical care facility may disclose medical information it maintains about a patient to a law enforcement agency except when (1) release of this information is not in the medical interest of the patient; or (2) the facility is a psychiatric care facility."

Section 132. Obtaining a specific record for a specific purpose which has been clearly identified and legally justified protects patients' rights. The same does not pertain to search warrants. We therefore strongly suggest the Committee consider excluding the use of search warrants.

Section 133(3). For reasons previously mentioned (i.e., trust and revelation of confidential information are integral and necessary to effective psychiatric treatment),

this section does not adequately protect psychiatric patients. We therefore recommend that it be amended to read: "If a member of the uniformed forces was a patient in a psychiatric facility, the medical information disclosed is to be limited to dates of treatment. If more information is required, the medical record will be reviewed by a psychiatrist who will indicate to the review board if further psychiatric evaluation is necessary in order to assure the person's emotional stability and reliability for continuation in the service."

Section 133(a)(4). This section deals with requests of a medical care facility for information on a patient's initiative. We recommend that the information may be released with specific authorization by that patient.

We appreciate having the opportunity to submit our comments and recommendations regarding this important bill and urge your Committee to seriously consider our comments as this legislation is finalized.

Sincerely,



Marcia Kraft Goin, M.D.
Chairperson
APA Committee on
Confidentiality

BOSTON PUBLIC LIBRARY



3 9999 05706 1002

